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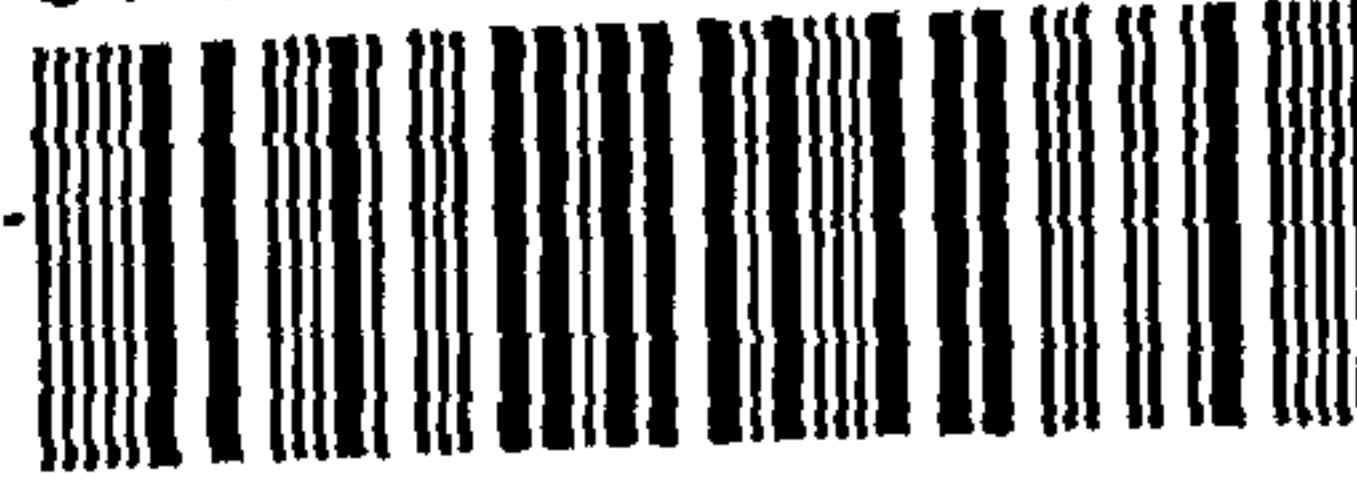
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U2184816

**“I’m a student, in a wheelchair”:
The experiences of disabled pupils attending
resourced provision in a mainstream secondary
school**

Doctorate of Education (EdD)

Date of Submission: February 2010

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STATEMENT OF ORIGINALITY

This study constitutes my own work. In addition neither the whole, nor any part of the study has previously been submitted for a degree or other qualification of any university or institution in the UK or elsewhere.

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ABSTRACT

Seeking pupils' views became an issue of national importance following legislation (Section 29A of the Education Act 2002, CRAE, 2008) and lack of such consultation in the United Kingdom has been repeatedly raised by the UN Committee on the Rights of the Child (1995, 2002 and 2008). The importance of seeking the views of *all* children about their experience is particularly salient since there is a legacy of exclusion and disadvantage for disabled children in mainstream school settings and provision historically has been planned and developed for them, without consulting with or involving them directly.

This study investigates the views and experiences of ten disabled pupils who attended a resourced provision attached to a mainstream secondary school. It used semi-structured interviews within a social constructivist paradigm carried out with disabled teenagers by a disabled researcher. The transcriptions of the interviews were analysed thematically with the categories for the analysis developed by grounded theory. Detailed consideration was given to the ethical issues raised by research which focuses on the need to promote the engagement of the children and ensure their voice is heard and these issues were addressed in the context of the present study.

The evidence from this study indicates that the pupils welcomed the opportunity to talk to a disabled researcher and were willing to explore their experience of being a disabled pupil in the school. They reported issues around transition to the secondary school with the resourced provision, feeling 'forced away' from their local community and from friendships established in their primary schools. They commented on bullying in the school and feelings of being perceived as 'different', as lesser human beings. Most of the children did not take on board the descriptor of 'disabled' for themselves, talking instead about their impairments, which they did not see as important to their sense of identity or self.

The conclusions reached stressed the need for teachers and policy makers to listen and respond to pupils' voice, taking into account individual needs, and engaging in joint problem solving with pupils at both an individual and systemic level. They need to be reflexive in their practice to avoid discrimination and support all children's rights and there should be increased awareness of the affirmative model of disability – we are valued for who we are, our disability is part of this and so our predicament and how we manage it should be accepted and valued as well.

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Chapter 1: LITERATURE REVIEW

1.1 Introduction to the study

This small-scale qualitative study investigates the views and experiences of disabled teenagers who attended a resourced mainstream secondary school in a large shire county. It adopts a social constructivist paradigm which recognises that experience is socially constructed by the individual through their negotiated interactions and the discourses which surround them in their home, at school and work, and in the wider world (e.g. the media).

In this research open ended, semi-structured interviews are used to ask the pupils about their social and academic experiences in school and to seek their views of their friendships and the support they receive. The study is an in-depth, rich picture of what school was like for these young people using a methodology which values their views and seeks to derive valid and useful interpretations grounded in what they say.

As the researcher, I too am disabled and have worked as an educational psychologist (EP) with disabled children in the county for over 20 years. As an EP I have always felt myself to be an advocate of the child rather than the interests of others I work with, e.g. parents, teachers, administrators. To do this involves a wide awareness of existing evidence bases regarding the ongoing debate around the inclusion of disabled children in mainstream settings. I was conscious of how little disabled children's own reflections on their experiences had contributed to the debate. There have been a number of studies which have sought the retrospective views of disabled adults on their school experience (e.g. Watson, 2002); there have been other studies which have sought the views of children as they experience or anticipate change or turbulence in their educational placements (Cook, *et al.*, 2001). These studies have usually used questionnaires or more structured interview or focus group methods. Some more recent studies have started to interview disabled children from a wide age range and with a broad range of special needs, attending a variety of provision, often with their parents or carers or teachers present, not always asking them directly about their school experience (e.g. Connors and Stalker, 2007). The present study is unique in that it focuses on year 9 cohorts of disabled pupils with physical impairments and associated learning needs in one school. Further it is carried out by a disabled researcher in an area where there is a relative dearth of such research. The open ended, semi-structured interviews were with a familiar, disabled adult who was not their teacher

or parent/carer and gave them anonymity and confidentiality within which to express their views.

This study followed a qualitative research paradigm and replication of the methods used may result in different viewpoints emerging in other settings. However the methods used can be replicated and there is a continuing need for further research involving disabled researchers investigating disabled children's issues. I hoped my findings would prove informative to the school itself and other institutions and to the local authority when reviewing its policies and that common themes would emerge within the broader body of academic research investigating pupil voice.

1.2 Introduction to the literature review

The experience of disabled children in school is shaped by a variety of factors. Disabled children's current experience of being in school has been determined by historical and socially constructed practices, driven by national legislation which is underpinned by models of disability and human rights and by local interpretation and enactment of this legislation. Disabled children in school encounter discourses of 'normality' and 'difference' arising from institutional factors and cultural practices. It has been argued that the main problem facing disabled children is that they live in a society which devalues their difference and sees their existence as problematic and undesirable (Watson *et al.*, 2000). However, these children can also be perceived as social actors trying to understand and control their experience and negotiate their complex identities within a frequently disabling environment. From this position they seek to establish friendships, develop social relationships and fulfil their aspirations alongside other children. Research into the experience for these children of being in school and the methods used to investigate this will also reflect the historical and social positioning of disabled people. One aspect of this is the place of disabled people within the research process and their full and informed involvement, including as researchers. Disability rights activists have promulgated the banner 'nothing about us without us' and have argued for the empowerment and self-determination of disabled people (Charlton, 2000). This research strives to promote the voices of the disabled children involved, through listening to and reporting their reflections on their experiences. In addition consideration is given to my own position both as a researcher and disabled person and the impact of this on the pupils' participation.

This research is situated within a social constructivist paradigm in the qualitative field of inquiry (Guba and Lincoln, 1994). This approach argues that we are all active agents in the

construction of our 'realities' and what we 'know' about the world. Thus we do not find knowledge, rather we construct it to make sense of our experiences and we continually review and modify these constructions on the basis of new experiences. In addition we do this in the historical and cultural context of our neighbourhood and society, and through social interactions with others (e.g. caregivers, siblings, teachers, peers, friends, partners).

This approach is opposed to an empirical, positivist and naïve realist position which suggests that there can be some universally attained understanding of the world and knowledge simply reflects these universal truths (Schwandt, 2000). Qualitative inquiry is applied to try to understand what the disabled young people in this study say about their experience of school life. It is acknowledged that this understanding will be generated on my interpretation of what they tell me, based on my awareness of the background, or context of their situations and my relevant beliefs, values, and past experiences. This interpretation aims to listen to these children's views, to give them a voice and to convey their messages to their educators for consideration in future educational policy decisions. Hence this qualitative inquiry is located within an emancipatory and transformative agenda (Howe, 1998; Schwandt, 2000).

In order to set the context further the existing literature will be reviewed in a number of key areas, first by considering historical perspectives on disability and then by examining the development of a range of models of disability and contemporary ideas, which suggest possible ways forward in exploring how these attitudes reflect certain constructions of disability which impact on the experience of disabled pupils and contribute to their self-identity.

Exclusion and disempowerment have been generic to the experiences of disabled children in education, particularly pre the 1970 Education Act. Section 1.6 considers the drive towards the inclusion of all pupils with special educational needs, including 'pupils with physical difficulties', in mainstream schools, which followed the 1981 Education Act and the recent legislation supporting this drive, e.g. the Disability Discrimination Acts (1995, 2005) and I consider the application of this in one local authority setting through the development of resourced provision (Section 1.7). Recent political commentary (Warnock, 2005) has begun to challenge and question the efficacy of placing all pupils in mainstream schools and the debate has once again resumed in the public arena (see, for example, Barton, 2005). The issue of rights versus efficacy is explored comparing positivist and ethnographic approaches to research evaluating the experiences and outcomes for these

pupils in the mainstream setting (Lindsay, 2003; Rudduck and Flutter, 2000). Positivist researchers have concentrated on evaluating certain adult chosen outcomes rather than considering the experience of the children from their own perspective and addressing the issues of importance to them (Section 1.8).

Sections 1.9 – 1.10 consider the need for the voice of the pupil to be sought and listened to and research that has been carried out *with* young people, rather than done on them will be explored. Research with young disabled people raises distinct issues regarding their informed involvement and engagement which need to be taken into account (Section 1.11 and 1.12).

In Sections 1.13 the existing literature on the experience of disabled pupils included in mainstream schools will be reviewed. Issues of their experience of ‘difference’, receiving adult support and friendship are particularly relevant in the context of the present study.

The conclusions that can be drawn from the literature review lead to the research questions which are addressed in this study and these are stated in Section 1.15.

1.3 Historical constructions of disability

As a starting point it is useful to consider the development of perceptions of disability from a historical perspective. The development of the education system might be considered to have proceeded in a linear, rational way; however the thinking and beliefs of older practices do not necessarily disappear as new policies and practices emerge. Relics of earlier beliefs can remain within later attitudes and practices (Armstrong, 2002). Further, it has been argued, concerning research into inclusive education, that often old practices continue as they were although new terms and labels are being used (Slee, 1998) and this can also be argued for the practice of inclusive education. Although new legislation requires policies under new terminology, this does not necessarily mean that practice has changed comprehensively.

Research into the history of disability is impeded by limited primary resources and in later periods those that do exist are mostly archived descriptions of formal services and treatment approaches from the standpoint of the professionals controlling the delivery of services (Braddock and Parish, 2001). However there are some useful accounts available of the treatment of disabled people from the time of the Ancient Greeks up to modern industrial society (e.g. Humphries and Gordon, 1992; Oswin, 1998; Braddock and Parish,

2001; Borsay, 2004) and how these societal attitudes towards disability has impacted on the treatment of disabled people and the development of social policy:

“Attitudes to disability have been influenced by a range of factors including humanity’s struggle to survive, religious beliefs, economic change, literature and art, scientific discoveries, medicine, philanthropy, politics and laws. The development of services for children growing up with disability has a history steeped in vacillating attitudes: extreme cruelty alternating with protection, neglect alternating with enlightened provision, exploitation alternating with respect” (Oswin, 1998, p. 29).

In early periods of history, where the need for a society to survive was prevalent, it is now widely accepted that disabled children were often killed and abandoned: “The Ancient Greeks, aiming to create the ‘perfect race’, always killed deaf children; the Spartans threw children with impairments into pits” (Oswin, 1998, p. 29). Disabled children might also be perceived as signs that their parents had displeased the gods; yet, frequently infanticide was also practiced for economic reasons, if a family had too many children (Braddock and Parish, 2001). In some exceptional situations where the family was powerful and wealthy, congenital deformities were not a barrier to success (the Roman emperor Claudius, being one such example). The development of religious ideals led to teaching that people with impairments should be protected and helped; both the Bible and the Koran contain such texts. Some religious interpretations have suggested that disability is a form of punishment for misdemeanours in a previous life or a manifestation of evil spirits (both Luther and Calvin claimed people with learning difficulties were filled with Satan). This perception can lead to a punitive attitude towards disabled people generally and shame and secrecy around disabled children. At different times in history such persecution has vacillated with protection. Throughout history it is apparent that the political and social climate of the time has impacted on the way disabled children are treated – they may be neglected, exploited, segregated, even hidden.

In the Middle Age there appears to have been two conflicting strands to the perceptions of disability. On the one hand, some disabilities, particularly deafness, epilepsy and mental illness, were seen to have demonic properties which led to the persecution of people with disabilities. On the other hand, with the widespread plagues throughout Europe, disabled people were seen as part of the general order, situated with poor people and generally

receiving support within their communities, when survival was difficult for everyone (Stiker, 1999).

During the Renaissance period the scientific method developed and this led to the exploration of treatments and attempts to ‘cure’ the disability. This era marked the beginnings of forms of education to overcome difficulties (e.g. the education of the deaf in Spain and the Ottoman Court described by Braddock and Parish, 2001).

A number of investigations into the history of disability adopt a ‘materialist’ approach, which ‘locates past experiences of disability within the political, social and cultural organisation of society’ (Borsay, 2004, p. 12), suggesting that it is society, not the impairment itself, which creates the disability. The treatment of disabled people since the industrial revolution is overviewed by Borsay (2004) who argues that ‘social policies have created and sustained the discrimination that continues to make disabled people excluded citizens’ (p. 1). Since 1750 disabled people have been excluded from full rights of social citizenship through ‘divisive practices’ such as segregated schooling, institutionalisation and separate training workshops which exacerbate this exclusion. This results in the ‘mixed economy of welfare’ where strong charitable support further promotes ‘divisive practices’. Colin Barnes, Vic Finkelstein and Brendon Gleeson (Barnes, 1997; Finkelstein, 1981; Gleeson, 1997) are all academics who posit that the transfer from feudalism to capitalism further excluded and disenfranchised disabled people from society, through the introduction of complex mechanised, standardised and unadaptable equipment to promote efficiency and maximise production and therefore profit. Such developments also standardised the workforce and ‘disabled’ those who were unable to operate the equipment.

“It was, therefore, the economic necessity of producing efficient machines for large scale production that established ablebodiedness as the norm for productive (i.e. socially integrated) living. For physically impaired people the machine determined their social status, rather than people determining the social significance of machinery – production for profit undermined the position of physically impaired people within the family and the community.” (Finkelstein, 1981, p. 3)

Other writers also suggest that both philanthropy and governmental policy and legislation have shaped the perceptions and segregation of disabled children (Oswin, 1998).

Influences such as the 1853 Lunatic Asylums Act, the establishment of the National Society for the Prevention of Cruelty to Children (1884), The Royal Commission on the Feeble-Minded set up in 1904, the 1944 Education Act and philanthropists such as Captain Thomas Coram, Dr Barnardo, Grace Kimmins and William Treloar together led to the establishment of segregated provisions to meet the needs of disabled children and adults. Because of these philanthropic interests blind, deaf and physically impaired children sometimes had the opportunity for a basic education and training for a trade, though they still had no rights, were not listened to or given choices (there were a few exceptions, e.g. blind children from wealthy families could 'rise higher'). There was a development of charity schools and homes for these children, many of which were used well into the 1970s and some of them were incorporated into local education authority or health authority provision. However, much of this provision was based on a view of disability as pathetic and tragic, for instance, the Chailey Hospital and School in Sussex was opened in 1903, inspired by Grace Kimmins, who in 1894 had set up the Guild of Poor Brave Things in London to give 'crippled children' outings (Oswin, 1998).

Another factor influencing perceptions of disability and attitudes towards disabled people has been the use of the terms and categories used to label and define 'types of feeble-mindedness', introducing terms such as 'morons', 'idiots' and 'imbeciles' (Hilliard and Kirman, 1965). The 1944 Education Act listed 11 categories of childhood impairment which would require the child to be educated in special schools. The use of categories still persists although these change over time, with new terminology introduced at intervals when previous terms begin to be seen as pejorative. In 1980 the World Health Organisation (WHO) produced an International Classification of Impairments, Disabilities and Handicaps (ICIDH) which was updated in 2001 to become the International Classification of Functioning, Disability and Health (ICF). As I shall discuss below in Section 1.4.2, moving from a medical to a social model shifts the emphasis from categorising and hence marginalising the individual towards challenging the organisation of society so that barriers to participation and inclusion are lifted.

Against this historical background a number of explanatory models of disability can be identified which aim to aid the understanding of disability in both research and clinical settings.

1.4 Models of Disability

1.4.1 The Medical Model

The medical model perceives disability as the result of some physiological impairment due to damage or a disease process, leading to a view of the person having a 'condition' which requires 'treatment'. The individual is the focus and the emphasis is upon changing the person to adapt to their environment, i.e. to try to become 'normal' through medical intervention, courage, independence and exertion of will-power. The 'medical model' is the main approach to understanding disability implicitly adopted in the provision of health care and in this context is illustrated by the World Health Organisation (WHO) 1980's model of disability (Johnston, 1996). This defines disability in terms of deficits in the performance of activities by an individual as the result of a physical impairment following disease or disorder - "a disablement is an impairment which leads to a person being unable to carry out certain activities that are considered in his or her family to be normal" - locating the issue firmly within the individual. Therefore the origin of disability is in individual pathology. Disability is contrasted with handicap, where a value judgement is made of the 'social value' of the individual's role in life on the basis of some implicit understanding of what is normal - handicap is "a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual" World Health Organisation (1980). It can be seen that this model has its origins in the historical aspects of disability described above, which maintained a focus on the individual's deficits and the need to rectify these. The 'charitable discourse' mentioned above is also implicit in this model and both position disabled people as disadvantaged or as having lives of lower value than 'able-bodied' people. These models, together with those described below can be used to help examine the attitudes of disabled people themselves.

The World Health Organisation updated its classification system in 2001 in an attempt to "put the notions of 'health' and 'disability' in a new light" by placing an emphasis on health and recognising the potential universality of impairment and hence disability. It has shifted the emphasis from 'cause' to 'impact' and claims to take into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. It sees neither the medical nor the social model (see below) as adequate on their own, but suggests both are partially valid. It adopts a 'biopsychosocial' model (World Health Organisation, 2001, p. 20), promoting both medical and social responses to the disability, depending on the circumstances. In the International Classification of

Functioning, Disability, Health (ICF) disability and functioning are viewed as interactions between health conditions and contextual factors, to allow for the impact of the environment on the person's functioning. Contextual factors include external environmental factors (such as social attitudes, architecture, etc.) and internal personal factors (such as age, gender, coping strategies, level of education, etc.). Disability is defined as involving dysfunctioning at one or more of the levels of impairments, activity limitations or participation restrictions.

The ICF still requires another person to make a judgment about the level of functioning of the disabled person, although this is structured in a detailed way and the ICF urges the assessor to be objective. This judgment is predicated on the negative aspects of functioning, activity and participation. As such it still has a lot in common with its predecessor and is 'theoretically underdeveloped' (Imrie, 2004), though it may have some value in defining and researching disability, particularly in medical fields (Shakespeare, 2006).

1.4.2 The Social Model

However, many disabled people reject being defined as abnormal or inadequate and this has led to rejection of the medical model in favour of a social model of disability, with increased emphasis on the importance of social factors in the maintenance of disability (Oliver, 1996). The social model argues that individuals who are perceived to be 'different' because of a physical impairment find that they are oppressed by societal views of normality and become more disadvantaged by the attitudes of society than by their loss of function (Llewellyn and Hogan, 2000). Disability only exists in so far as it is socially constructed and imposed on people with impairments (Hutchinson, 1995). Disability is redefined in terms of disabling environments, disabled people are seen as citizens with rights and the responsibility for creating, sustaining and overcoming disablism is relocated at societal level. Oliver (1995) refers to the 'hegemony' or the totality of the experience of being a disabled person, in a society which excludes those who are different or unable to compete. If society is organised around co-operation and collaboration, then disabled people can be included in education, employment, culture, politics and community. A fundamental issue in contemporary Western discourse on disability is the cultural assumption that 'sameness' or 'similarity' is always desired by those in society (Stiker, 1999). This leads to an intolerance of diversity and individualism, though it can be argued,

and some cultures recognise, that difference is not only acceptable, but also desirable and necessary.

The alternative historical materialist approach drawing upon recent political analyses, (Gleeson, 1997; Borsay, 2004) contributes to this political view of the experience of disability. Gleeson (1997) argues that the preoccupation with what terminology to use, with reinventing titles for disabled people “is characteristic of a vacuous humanism which seeks to emphasise a ‘human commonality’ over the material reality of oppression” (p. 182). For people with impairments then “the social history of capitalism appears as a sociospatial dialectic of commodification and spatial change which progressively disabled their labour power” (p. 195). Oliver (1990) and other materialists, contrast the situation for disabled people in feudal society with the experience of disablement in capitalist societies. “Impairment hasn’t always been associated with dependency, and material change may liberate disabled people from contemporary forms of oppression” (Gleeson, 1997, p. 192).

The emergence of the social model of disability in the UK and its development in the 1970s by activists in the Union of the Physically Impaired against Segregation (UPIAS), has enabled disabled people to recognise themselves as oppressed and as it has become increasingly powerful, disabled adults and their allies have been proactive in claiming participation in mainstream society as a civil right. For example, in the Disabled People’s Rights and Freedom Bill, proposed and drafted by the British Council of Disabled People (BCODP), disabled people have claimed that the draft Disability Discrimination Bill in 2004 was too weak since it was not based on the social model of disability, that it continued to allow discrimination against disabled people in many areas of life and did not protect disabled people’s human rights and that the ability of disabled people to enforce their own rights continued to remain very limited (Rickell, 2004).

Whilst most disabled activists would argue that the social model has offered a liberating and emancipatory influence on disability politics and research, including the promotion of research by disabled researchers, some problems have emerged with its use in practice. Jill Humphrey, a non-disabled academic-activist researching disability politics in UNISON (Humphrey, 2000) suggests that the social model in practice is grounded on the premise that ‘disabled’ and ‘non-disabled’ people are in opposition to each other and this premise leads to there being no scope in the model to deal adequately with those who cross over

between disabled and non-disabled worlds, or those somewhere on the periphery, e.g. those who have not accepted or claimed a disabled identity. In terms of politics, this leads to a separatism which closes doors to coalition and transformation. She suggests that one's 'identity' with a minority group should be tied in with 'issues' and 'ideologies' to allow for possible coalitions with other groups and supportive activists and researchers who do not qualify for entry into the minority group. She goes on to suggest that

“....the concept of ‘normalising regimes’ could hold a key to forging coalitions between differently disabled people and other stigmatised peoples and reflecting back to non-disabled people the precariousness of their ‘normality’. However a key is not about locking ourselves in: it is about opening a door outwards.” (Humphrey, 2000, p. 82)

Danforth (2001) uses the philosophy of pragmatism to evaluate the ‘functional limitations’ model (which appears to equate with the medical model), the ‘minority group’ model (identity politics) and the ‘social constructionist’ model. He argues that ‘Knowledge or belief, to the pragmatist, is only valuable as a predisposition toward useful, worthwhile action in the social world’ (Danforth, 2001, p. 344). Danforth (*op cit*) concludes that a democracy must accept the different viewpoints of its members and that a consensus view is not necessary. He concludes that a wide range of different conceptualisations and perspectives is important to promote discussion and exploration and the models should not be seen as in competition for one, best way of thinking, but one should take the best and criticise the worst from each model. I suggest that there is a danger here in that the models have very different implications for particular groups in society and some models, such as the medical and tragedy models, are oppressive in the value judgement they attach to a life lived with physical or learning impairments.

Further criticisms of the social model have been raised from within a social model perspective by a number of academics (Morris, 1991; French, 1993; Pinder, 1995, 1996; Thomas, 1999; Shakespeare, 2006), specifically in relation to the denial of the impact of impairment ‘problems’ on a disabled person’s life. The removal of external, disabling environmental and attitudinal barriers would still leave some individuals with physical impairment experiencing pain and fatigue, or impoverished because they are unable to

carry out tasks valued in the employment market. This has led to a claim of ‘universalism’, which takes a different perspective. In this construction of disability, everyone is seen as likely to experience impairment therefore those currently non-disabled are ‘temporarily able-bodied’ (Shakespeare and Watson, 2001) and that “there is no qualitative difference between disabled and non-disabled people, because we are all impaired” (Shakespeare and Watson, 2001, p. 27). However, other writers have claimed that there are dangers in this ubiquitous approach in that disability may be seen not to matter (Hughes, 2007) and the social and political drive given to the disabled activist movement by the social model may be lost.

Critiques which have centred on the inclusion of pain and illness and personal experience within the social model have been strongly resisted by some disabled activists. For example Finkelstein (1996) and Oliver (1996) both argue that the effect of considering personal experience and pain is to dilute the effectiveness of the social model; other writers such as Thomas (1999) and Shakespeare (2006) stress the limitations of the social model if it cannot adapt to include the individual’s personal experience as well as societal barriers. Further criticisms of the social model also suggest that whilst important in asserting the rights of disabled people, it does not address ethnic diversity and the impact of social and cultural constructs in different ethnic groups on the experience of impairment (Atkin and Hussain, 2003).

Some writers express concern that the concept of disability would disappear altogether, as an implication of the social model. MacKay (2002) argues that over-simplifying or over-generalising disability would lead to a failure to recognise and a failure to provide for individual need and so lead to a failure to acknowledge disability as part of human diversity. He is particularly concerned that those people with intellectual difficulties are being marginalised and overlooked by current models and perceptions of disability. He suggests that the complexity of disability should be respected and responded to with honesty, vision and intelligence and that there is a need to acknowledge the heterogeneity of the group ‘disabled’ where there are as many differences as similarities. Further criticism of the limitations of the social model has been raised by Llewellyn and Hogan (2000) “Practitioners within the clinical professions have viewed the social model as denial of what is an objective truth about ability and claim that the social model does not adequately address how we can identify individual truth, perceptions and belief about disability (Hutchinson, 1995)” p. 160. Shakespeare and Watson (1997) are disappointed that the social model has not been more widely accepted in the academic world and that

non-disabled academics and commentators continue to see disability as personal tragedy. They claim that psychology individualises disability whilst medical sociology pathologises disability. They feel that these disciplines provide limited insights but are no substitute for the social model. The differences which exist within the disability movement on the issue of the social model (e.g. the need to include personal experience and to consider pain and illness) are not as important as the suspicion and hostility with which the social model is greeted in the wider world. Shakespeare and Watson (1997) suggest that they fight for a social model analysis in society as a whole, drawing on feminist and post-modernist accounts as well as a materialist world view. However, the social model developed in the early 1970s, in representing a dichotomy with the medical model, may now be inadequate for disability research in the 21st century and the incorporation of the impact of impairment on the individual, as well as disabling environments and practices, needs to be taken into account, “People are disabled both by social barriers and their bodies” (Shakespeare and Watson, 2001, p. 15).

1.4.3 The Interactional Model

The significance of both individual impairment and social and environmental barriers can be developed into what Shakespeare (2006) describes as an ‘interactional’ model of disability, where disability is seen as always being an interaction between individual and structural factors, such that total removal of external barriers will not eliminate disability because there will still remain intrinsic factors such as the nature and severity of the impairment and the individual’s attitudes towards it. This recognises that coming to terms with their impairment is important to disabled people, and finding ways to handle their ‘predicaments’ (Shakespeare, 2006) – “to understand it as a difficulty, and as a challenge, and as something which we might want to minimise but which we cannot ultimately avoid” (p. 63) - is a necessary accommodation disabled people must make. This is the reality of impairment, not to be regarded as a tragedy or identity-defining flaw, though society frequently assumes that disability is ontologically problematic, with such practices as selective abortion, pre-natal screening and euthanasia. (Hughes, 2007). Shakespeare sees the interactional model as an improvement on Thomas’ (1999) social relational model of disability (“wherein disability is conceptualised as the social imposition of restrictions of activity on people with impairments”, p. 123 – an unequal power relationship, accompanied by “the socially engendered undermining of their psycho-emotional well-being”, p. 124), developed as the result of qualitative research with disabled women. Thomas defines disability solely in terms of social oppression, whilst Shakespeare argues that this is a circular argument and does not allow for the positive dimension of social

relations which enable people with impairment. In contrast the interactional model of disability looks to balance individual (medical) and social aspects and work within this model emphasises three issues which influence inclusion in society – individual factors, including personality and skills as well as impairment; societal factors, including accessibility and attitudes; and factors within the system of support available to the person, i.e. social support, professional care and assistive devices (Van den Ven, 2005). As such this approach aims to capture the complexity and diversity of the life experiences and circumstances of disabled people. However, whilst this model has been considered by disabled academics it has not yet been applied consistently within research with children, though there are now some studies emerging which seek the perspective of children and young people and consider their experiences within this model (see Section 1.13).

1.4.4 The Affirmative Model

An extension of the social model perspective is proposed by Swain and French (2000). They go further to suggest that the ‘disability divide’ is not one between having impairments and not having impairments but rather is one between different perceptions of disability, in terms of the meaning it has in people’s lives and social identity. They argue that the social model redefines ‘the problem’ (i.e. disability) as not caused by the impairment or functioning of the individual, but by an oppressive disabling society. In this way it would seem that the social model does not liberate disability from the ‘tragedy’ view but promotes this perception, albeit from a different angle. Being seen as an ‘oppressed person’ as the social model suggests is tragic and having impairments can still be seen as tragic. They go on to promote an ‘affirmative’ model of disability as a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people, grounded in the benefits of the life-style and the life experiences of being impaired and disabled. They draw on work from the Disability Arts movement, quoting a song by disabled activist Johnny Crescendo entitled, ‘Proud, angry and strong’. They claim that divisions between those who are disabled and those who are non-disabled cannot be made on the grounds of impairment or whether one group is the oppressed or the oppressor. Rather, the divide is due to the perceptions of disability that are held. Swain and French (2000) argue that non-disabled people can accept the social model but are much more threatened by the notion that a wheelchair user could be pleased or proud to be the person he or she is. The non-tragic or affirmative view of disability is not about the ‘problem’ but about “disability as a positive personal and collective identity” (p. 571). The affirmative model “signifies the rejection of presumptions of tragedy, alongside rejections of presumptions of dependency and abnormality” (p. 578).

1.4.5 Other Models

In analysing the medical and social models from the point of view of clinical practitioners, Llewellyn and Hogan (2000) suggest that two further models, from developmental psychology, might build on the social model (which was created by disabled people themselves), to better encapsulate the complexities surrounding the disabled child in various settings. They suggest a systems analysis approach which examines the dynamics in the interaction between the characteristics of the person and of the environment they are in, which can vary across school and home.

“Bronfenbrenner (1989) reminds us that the characteristics of the person at a given time in his or her life are a joint function of the characteristics of the person and of the environment over the course of that person’s life up to that time.” (Llewellyn and Hogan, 2000, p. 160)

The application of a systems analysis model allows the possibility of examining the mutual influences of the school community, the education system, and the self. In addition to the self-perception of the young disabled person the viewpoints of significant others in these settings will also be important, e.g. parents, peers, teachers. This approach is seen to be one of discovery and exploration where the aim is not to test hypotheses but to generate them. The importance of the ecological framework to the exploration and understanding of the young person’s experience is emphasised because “all environments in which the young person interacts will have a different impact upon their functioning and psychological well-being” (Llewellyn and Hogan, 2000, p. 161).

They further supplement this with the transactional model which offers an interactionist perspective which they claim can build upon the social model of disability, such that disability is not only created and maintained by non-supportive environments, but also caused and sustained by problematic social relationships. So a disabled child in a mainstream school may be seen to be ‘more different’ and other people’s opinions and reactions have been seen to be important in determining the way children feel about themselves (Harter, 1986) and how they react to challenges (Johnston, 1996). Llewellyn

and Hogan (2000) argue that the transactional model reminds the researcher or clinician to analyse the development of social relationships surrounding the child.

Both the systems analysis and the transactional models look at how interaction in different contexts can impact on psychological well-being. In addition to the interactional and affirmative models, these additional perspectives take forward the development of disability research from the dichotomy between the medical and social models and help to aid understanding and inform research and clinical practice in particular settings. The social model still carries forward the “political imperative to remove disabling barriers” (Shakespeare and Watson, 2001, p. 15), whilst further refinement and thinking by researchers in this field are allowing for more complexity to be considered in disability research.

These explanatory models of disability reflect different ways of thinking about disability and the model operating in a given situation will result in certain messages being conveyed regarding perceptions of and identities attributed to people with physical and learning impairments. These messages are conveyed through social interactions and they will affect how disabled people think about themselves and others and contribute to the construction of their identity. Many disabled people will grow up within families and school environments which promote the tragic perception of disability (Thomas, 1998; Connors and Stalker, 2007). In addition, many people become disabled later in life having constructed understandings and lifestyles as non-disabled people. We are surrounded by negative and tragic images of disability promoted by the media, both in print and visual (Rieser, 2003, Shakespeare, 1994). In her earlier work, French (1993) emphasises the social model while retaining an awareness of the complexity of disabled experience and she has argued that to establish a disability movement which aims to improve the lives of disabled people, it is necessary that the social model should become more widely shared. This is beginning to happen (e.g. Connors and Stalker, 2007; Gwernan-Jones, 2008) and might be enhanced by extending thinking to include the affirmative model of disability described above.

The present study seeks to locate itself within a philosophy which takes into account the social model approach, enhanced by these developing, additional perspectives of the interactional and affirmative models and considers the experience of disabled pupils, from their perspective, whilst recognising that participants' perspectives may reflect or encapsulate aspects of the other models described above.

In this work I have chosen to use terminology to describe my participants with explicit reference to my understanding of disability in the context of the explanatory models I have described. I have used the term 'disabled pupils' in order to avoid allegiance to the medical model - I feel able to use this term because these pupils are identified as such by the way society and its institutions and expectations are organised.

1.5 Self-identity

Marxist thought considered individual identity to be a product of a person's class position, with capitalist societies promoting a range of ideologies which blind working class people to the nature of their economic oppression (Riddell and Watson, 2003). This thinking has been extended by disabled political activists to the position of disabled people, suggesting that society promotes images of disabled people as either more or less than human (Oliver, 1990). In addition, it is suggested that these images impact on the self-perceptions of disabled people, resulting in lowered expectations and oppression:

“As well as influencing thinking within the wider society, these negative ideologies affected the thinking of disabled people themselves, limiting their sense of social and political possibilities. The disability movement, emerging during the 1970s and 80s, took on the task of raising political consciousness so that these limiting ideologies could be challenged and disabled people could develop a far more positive identity” (Riddell and Watson, 2003, p. 10).

The development of self-identity is of key importance for young people during adolescence as their self-concept becomes more differentiated and complex than that of their childhood and they become more able to think of themselves in abstract rather than concrete terms (Rosenberg, 1986). Socialisation experiences during interactions with caregivers, peers, teachers and in the wider sociocultural contexts of the home and school will influence the

development of a young person's self-representations in both a global (self-esteem) and 'domain-specific' (self-concept) sense (Rosenberg, 1986; Harter, 1999).

“Although cognitive-developmentalists emphasise the fact that children are active agents in their own development, including the construction of self; those from the symbolic interactionist and attachment perspectives alert us to the fact that children are also at the mercy of the particular caregiving hand they have been dealt” (Harter, 1999, p. 9).

Harter (1999) also notes the importance of language and its evaluative function and the development of social awareness which allows for comparison with others, which can lead to feelings of inadequacy and incompetency. The self becomes a social construction, crafted through linguistic, i.e. symbolic interactions with others: “the personal self develops in the crucible of interpersonal relationships with caregivers” (p. 12) and, later in life, through interactions with others, such as peers and teachers.

There is an implicit assumption that children with various medical disorders and physical impairments might hold less favourable perceptions of their own competence because of the compromising nature of their condition although this assumption is not supported by the empirical literature (Harter, 1999). Harter found that there were no significant differences in the self-perceptions of a hospitalised group of chronically asthmatic children than the normative samples. These children were under heavy medication which resulted in side effects affecting physical appearance, but their self-perception of their physical appearance was the same as the norms. Similar effects have been found for young physically disabled athletes and children with cancer, diabetes and hearing impairment (see Harter, 1999). She suggests a range of possible explanations such as: the children making comparisons with other children with similar medical conditions (similar social reference group) rather than 'normal' children; socially desirable responding; unconscious denial; confusion between the real self and ideal self; what she calls a 'healthy adjustment to self-standards' – the children have adapted to reality and feel they are actually doing quite well relative to the limitations of their condition. Harter concludes that it is not yet clear from these questionnaire studies what is the possible explanation for such results and further investigation is required to better understand the processes underlying these self-evaluations. However, the possible explanations she gives continue to beg the assumption that these children and young people should have lower self-perceptions which may in fact

reflect the negative perceptions of the researcher regarding physical impairments and perceived disability.

Recent research which has sought to obtain the views of children and young people regarding the impact of their experience of disability upon their self-perceptions has suggested that this has little significance for their self-identity (Watson, 2002; Skar, 2003). However, when they reported how others saw them, they did mention disability and impairments, often feeling they were judged on the basis of these (Skar, 2003). Studies have found that disabled adolescents would not mention their impairments on the telephone when talking to someone who did not know (Singh and Ghai, 2009) and those who use social networking sites on the internet, frequently do not reveal their impairments to their internet 'friends', preferring to remain anonymous in this respect (Skar, 2003; Clark, 2009) perhaps to avoid such 'judgments' by others, though Skar (2003) suggests it "helped them to feel like any other adolescent" (p. 641).

It has been argued that it may be necessary to consider the interaction of identity in relation to the type of impairment (Gwernan-Jones, 2008). Particular disabilities may be more heavily stigmatized and have poorer life outcomes (e.g. intellectual disabilities, Beart *et al.*, 2005) whilst there are also issues of a lack of self-awareness and less likelihood of discourses leading to a positive identity as intellectually disabled in that this disability is experienced rather than discussed (Beart *et al.*, 2005; Goodley, 2003). Self-advocacy groups, facilitated by non-intellectually disabled, can lead to positive personal and group identity (Goodley, 2000, 2003). Similarly adults with dyslexia have reflected on their negative school experiences, but have come to conclude through their life experiences that they are not 'stupid', and have been able to achieve a positive dyslexic identity through group support (Dale and Taylor, 2001; Burden, 2005). Deaf people have argued that they are a minority language community rather than disabled people, though their impairment becomes more evident when they want to interact and communicate effectively with the hearing community. Although it is empowering to learn sign language and become part of the Deaf community, this can also be limiting and exclusionary, though it can be argued from a social model perspective, that this is because hearing people do not know sign language. It has been pointed out that Deaf students who reject an identity of disability also receive disabled students allowance (Skelton and Valentine, 2003) but do not see this as a contradiction, but a practicality to overcome the societal barriers of how education is organised.

Recent research linking disability identity with other identities such as race and gender, reveals the multiple identities held by participants, some held more strongly than others and becoming particularly salient in certain circumstances or places (Ahmad, 2000; Atkin and Hussain, 2003). The definition and experience of disability is greatly influenced by the social relationships and cultural influences which surround the individual.

“Some, for instance, argue for a more considered approach that recognises that disability might be only one aspect of an individual’s identity. This further suggests that impairment can only be understood against what is considered as ‘normal’ for someone of their own age, gender and social class (Ahmad, 2000). Normalcy is not a given universal and impairment needs to be seen in its social and cultural context” (Atkin and Hussain, 2003, p. 162).

Thus identity issues are complex, multiple and fluid and frequently imposed on the individual through the perceptions and categorisations of others, often more powerful than the person with the impairment themselves. Identity can also act as a resource if chosen by the individual to demonstrate a connection to others in a particular, politically active group (Oliver, 1990). The experience of being a *disabled* pupil in a mainstream school with an earmarked resourced provision will have implications for these pupils’ self-identity and this is a focus of the present study.

1.6 Drive towards inclusion

In parallel with the development of models of disability described above and influenced by it, has been the drive towards inclusion in educational settings. At the turn of the twentieth century children with physical impairments were considered to be ineducable and were often cared for in charitable institutions segregated from both their families and mainstream society (Alderson and Goodey, 1998). Since the 1921 Education Act, the medical model of disability has played an almost exclusive role until very recently in the decision making process of educational placement for disabled children (Marks, 1997). This process has been influenced by subsequent legislation which has aimed to change the way disabled children are educated. The 1944 Education Act stated that all children considered educable should have access to schooling, but may have to attend segregated special schools (Alderson and Goodey, 1998). By 1970, it was finally acknowledged that this system was failing a large number of disabled children and the Education (Handicapped Children) Act (1970) was passed (enacted in 1971), giving Local Education

Authorities the responsibility for the education of all children, regardless of the severity of their disability. Following this the Education Act (1976) stated that all 'children with special needs' should be educated in mainstream schools, if possible, though this section of the act was never implemented. It was closely followed by the Warnock Report in 1978 (DES, 1978) – a select committee review of the 'Educational provision for children with special needs in England, Scotland and Wales', which formed the basis of the Education Act (1981) and put the issue of 'special educational needs' on the national agenda for the first time as well as giving credence to parental views. The 1981 Education Act (enacted in April 1983) supported the principle of educating disabled children in mainstream schools where appropriate, taking account of parents' wishes, and ensuring three conditions were applied: that the child's needs could be met in the mainstream setting; that this would not adversely affect the education of the other children and that it was an efficient use of resources. It was still anticipated that segregated special schools would be necessary for some disabled pupils and it introduced the bureaucratic assessment and statement procedure (Vaughan, 2002).

In 1992 an Audit Commission and Her Majesty's Inspectorate Report (Audit Commission/HMI, 1992) heavily criticised the practices and procedures which had developed from this Act and the Education Act (1993) reformed these, whilst continuing with the same principles and strengthening duty to comply with the wishes of parents.

From an international perspective a rights agenda has also tried to drive forward inclusion. In 1989 the United Nations Convention on the Rights of the Child (United Nations, 1989) promoted, amongst other things, the rights of all disabled children to be included in mainstream schools. A number of the articles give support to this: the convention was ratified by the UK in 1991, showing acceptance of responsibility for the obligations within it. In addition the United Nations Salamanca Statement in 1994 endorsed that inclusive education should be the norm (UNESCO, 1994).

The inclusion of disabled pupils in mainstream settings is thus currently high on the political and educational agenda. As we have seen, historically pupils with physical impairments and associated learning difficulties have been excluded from mainstream educational environments, not least because of the physical inaccessibility of these environments (Bethell, 1995). Other issues which have blocked inclusion have been the attitudes towards and expectations for the life outcomes of disabled children by society. As Mason and Rieser (1994) have claimed:

“Inclusion is a challenge to the long-standing, traditional approach that regards impairment and disabled people as marginal or an ‘afterthought’, instead inclusion promotes that impairment and disablement are a common experience of humanity and should be a central issue in the planning and delivery of human services such as education” (p. 41).

The social model is beginning to have an impact on educational research and on current educational thinking regarding overcoming barriers to learning to enable successful inclusion of all pupils in mainstream settings (Thomas *et al.*, 1998; Booth and Ainscow, 1998; Ainscow, 1999, Connors and Stalker, 2007). However, it is apparent from recent government legislation and guidance (e.g. DCSF, The National Strategies Inclusion website, 2010) that medical model thinking still dominates: the use of language such as ‘special needs’ in itself implies exclusion, suggesting a difference between ‘normal’ and ‘less than normal’ (Barton, 1997). In addition some disabled activists stress that educational inclusion is not an object that can be achieved by politicians, policy makers and educators, but rather, is a process and is part of a wider commitment to the inclusion of all disabled people in society (Oliver, 1996).

The situation regarding inclusive education is changing at a faster pace than in any previous decade, because of legislation and government policy enacted at the start of the new millennium in England (Disability Discrimination Act (DDA) 1995, 2005; Special Educational Needs and Disabilities Act (SENDA) 2001; revised Special Educational Needs Code of Practice 2001; Accessible Schools: Summary Guidance, DfES, July 2002; Inclusive Schooling, DfES 2001; the Children’s Act, 2004). The SENDA amended part 4 of the DDA, making it unlawful for schools, colleges, universities and providers of adult education to discriminate against disabled people. Providers of education can no longer treat disabled people less favourably and they are required to make ‘reasonable’ adjustments. Local authorities (LAs) are charged with a responsibility to audit the access needs of their schools and have been provided with additional central government funding to improve access in all mainstream schools. As a result, more pupils with physical impairments now have the option of attending their local, neighbourhood school along with their peer group. The availability of this option should continue to grow, since both the LAs and schools now have a planning duty to continue to develop the capacity of mainstream schools to meet a wider range of needs (see also the Audit Commission’s report, *Special Educational Needs: A Mainstream Issue*, December 2002). Schools have

also been charged with a duty to promote disability equality in the same way as they currently promote race equality. However, there was backlash promoted by the media and special school lobby which was anti-‘rights’, and saw segregation as acceptable (Warnock, 2005), ignoring evidence of the positive results of inclusive education (Barton, 2005). Indeed ‘inclusive’ education has been constructed as also covering being ‘included’ in a segregated school (e.g. Cigman, 2007).

The Children’s Act in 2004 placed a new duty on LAs to produce and publish an overarching strategic plan for all children in their area by April 2006. Non-statutory guidance was produced by DfES in 2005 which recommended, amongst other things, arranging special events to consult with disabled young people.

Progress has been slow and in October 2006 Mencap produced a report of an analysis of the new Children and Young People’s Plans (CYPPs, DfES, 2005) required by the 2004 Children’s Act, of a representative sample of 20 local authorities (LAs), looking at the extent to which disabled children had been included, how the local authorities had integrated the CYPP with their duty to produce a Disability Equality Scheme and any examples of good practice (Every Disabled Child Matters, 2006). Although seventeen of the LAs contacted had published their CYPP by July 2006 (having been required to do so by April 2006), analysis of these suggested that there was a lack of plans with measurable actions for disabled children though many LAs had identified this as a priority. Where actions existed they were often vague, e.g. ‘develop integrated and responsive services’. The authors noted some planning for education but virtually none for housing and transport, both vitally important for disabled children and their families. Most LAs had not consulted with disabled children or their parents to develop their plans and LAs had not taken into account major changes in the numbers of disabled children in their area and their increasing need for services. There was no evidence of work being underway to develop a Disability Equality Scheme, which should have been published by December 2006. New government guidance was published in January 2009 and it is expected that all LAs will need to develop new CYPPs by 2011. There is a continuing central government push to improve mainstream provision to include all children, by targeting resources and communication through labels such as ‘Special Educational Needs’ and ‘disability’.

The Department for Children, Schools and Families produces termly ‘Special Educational Needs and Disability’ updates which report on recent key developments for pupils with SEN and disability. The on-line issue October 2008 indicated the present government’s

emphasis on improving the achievements of pupils with SEN and disabilities ('Narrowing the Gap', a two year project started in June 2007) and the implementation of the Children's Plan (December 2007) aiming to promote the right of every child with SEN and disabilities to reach their full potential. It is notable that the issue also mentioned 'Tackling Bullying' and reminded schools of their statutory responsibilities to eliminate disability-based harassment through implementing their Disability Equality Duty. The same issue still exhorted schools to seek their copy of 'Implementing the Disability Discrimination Act', a training resource produced by the then Department for Education and Schools in 2006, and still not yet received by all schools.

1.7 National policies in a local context: The development of resourced provision

The current research took place in one particular shire county local authority (LA).

Historically the policy initiatives described above have been reflected in the development of the LA's strategy for 'pupils with physical disabilities' (the term used within the authority) at secondary school level. This aimed to offer a range of provision, but physical access difficulties meant that until 1990, those pupils with significant physical impairments usually attended a special school. A major special needs review was carried out in 1990, following the implementation of the 1981 Education Act in 1983, which identified a need for more 'pupils with physical disabilities' to be able to attend mainstream schools in county (Hampshire County Council (HCC), 1990) in order to meet a requirement of the Act that 'wherever possible, children should be educated in mainstream schools'. In spite of this stipulation the number of children in separate, specialist provision in the LA had increased in the five or six years following the implementation of the Act in 1983 (Education Act, 1981). However, the financial cost of the major modifications required in some schools, particularly at secondary level, generated a staged policy for development over time in terms of programmes of adaptation. It was agreed that County policy would be to identify a number of such schools at geographically strategic locations across the county, and that these schools would be resourced, both through physical adaptations and equipment, and enhanced staffing levels, to cater for 'pupils with physical disabilities' (HCC, 1990). This was the start of a *resourced school model* in this LA. Criteria (HCC, 1990) were set for the identification of such schools which included the positive attitudes of head, staff and governors towards meeting special educational needs (SEN), evidence of a whole school approach to SEN supported by written policy statements and the school's development plan, and evidence of good practice in such matters as home-school liaison, links with the local community and with local primary schools willing and able to meet the needs of pupils with physical impairments and good contacts with external agencies and

support networks. Other criteria covered the availability of accommodation which had potential for adapted use, a 'medical' room on site with a school nurse, and geographical location that was easily accessible to children from an area larger than the normal catchment area. This policy demonstrated some shift in thinking in resource planning and provision in the LA from the medical model, where the individual is the primary focus and must 'achieve' the necessary skills or abilities to attend a mainstream school, to an application of the social model, in the planned removal of physical and attitudinal barriers through the identification and resourcing of the resourced school. However the shift was limited and confined by the LA's financial planning and did not include a "pedagogy for diverse learners, and...a consistent and explicitly inclusive policy framework centred on children's rights" (MacArthur *et al.*, 2007, p. 100). Other researchers have found that although the language of inclusion, based on the social model, may be used by LA officers, a deficit model is still the language used in planning in schools (Ramjhun, 2001).

The first fully resourced mainstream secondary school in this LA was completed in 1994. By the end of the decade four of these schools were in existence in different parts of the county, catering for pupils from a wide geographical radius. In addition, in recent years, pupils have applied to attend mainstream schools more local to their homes, and adaptations and provision have been made for them. Major differences between such provisions are the level of financial resources available to support the pupils which is significantly higher in the resourced schools; the number of staff trained to meet the needs of such pupils within the school, again higher in resourced provision, and the fact that the resourced schools have a higher number of pupils with significant physical impairments in the school as a percentage of the total population, thereby offering a peer group of other pupils with physical impairments within the school. There has been no further move to specifically create resourced provision, though ongoing auditing and mapping of accessible primary and secondary schools, across the county began to take place in 2003. Again, this may be perceived as movement towards social model thinking in developing provision within the county, whilst maintaining the vestiges of previous beliefs (Armstrong, 2002).

Cuckle and Wilson (2002) describe the features of a typical resourced provision in the context of their work with pupils with Down's Syndrome (*sic*). They note that access to the provision is variable, with less pupils attending secondary than attended similar provision during the primary phase. Two advantages with the resourced provision are access to role models of appropriate social behaviour, whilst also having "access to friends with similar needs and whose levels of maturity and interests maybe more evenly matched to their

own” p. 70. However, a disadvantage is that pupils are not attending their local schools and so these local schools may not then develop their own potential to become inclusive: “channelling resources and expertise into a few schools may undermine the inclusivity of the majority” (Sheehy and Nind, 2004, p. 64). In addition from the pupils’ point of view their friends are outside of their own neighbourhood and they have difficulties maintaining social contacts and experiences outside of the school day.

The decision by this LA to pursue what at the time was termed ‘integration’ into mainstream for disabled children by establishing resourced provision in mainstream schools was based on the requirements of the 1981 Education Act which

“ places a duty on LEAs to educate children with special educational needs in ordinary schools. The LEA must take account of the views of the parents, the child’s needs and its duty to provide efficient education for all children and use resources effectively” (HCC, 1990, p. 6).

The LEA did not draw on a research evidence base to justify its policy decisions, but drew from a rights agenda, backed by national legislation. I will now consider the conceptual perspectives which have been taken in guiding research into inclusion, in particular with regard to the distinction between rights and efficacy.

1.8 Rights versus efficacy

Disabled activists (e.g. Barton, 2005) argue that the issue of segregation versus inclusive education is not simply about resources or different educational philosophies but with fundamental values. It is about different conceptions of what is a good society, of images of self-identity and the relationship between education and society. We need to ask ourselves what sort of society we want, and what is the role of education in creating and maintaining that society. Barton (1995) discusses the human rights issues of participation, choice and empowerment as justification for inclusive schooling. He argues that current educational policies result in a diversified and hierarchical form of schooling which makes it difficult to improve institutional discrimination in the form of segregated schooling.

Outcome studies, which have attempted to determine which settings (i.e. along a continuum from segregated to inclusive provisions) have better ‘outcomes’ for pupils, have been inconclusive and have also been heavily criticised in terms of methodological

weaknesses (Ramjhun, 2001; Lindsay, 2003). They typically demonstrate a failure to control for many factors such as ability, degree of impairment, home background, social class, and environmental factors, etc. “It was unrealistic to expect such complexity to be reduced to a level where reliable and valid measurements could be made” (Ramjhun, 2001, p. 24).

Hegarty (1993) carried out a major international review of the literature and did not find a clear advantage for segregated provision over inclusive provision. He argues that because of this it is prudent to support inclusion because the human rights, moral and ethical reasons for inclusion are not undermined by any firm evidence of the efficacy of segregated provision. Other writers have suggested that “it could be argued that empirical research evidence is unnecessary for justifying inclusion since inclusion is a moral issue, one that is concerned with the type of society we want to design and live in because we value human rights” (Sheehy *et al.*, 2005, p. 32). The United Nations Convention on the Rights of the Child (1989), of which the United Kingdom is a signatory, has several articles of relevance here, including *Article 23* which relates specifically to disabled children and asserts their rights to enjoy a full and decent life, to dignity and self-reliance and to active participation in the community. As children, disabled children also have every other right in the convention too, including the right to non-discrimination (*Article 2*) and to be consulted on matters affecting them (*Article 12*). It is apparent that quantitative empirical methods are not moving us forward in the inclusion debate and more qualitative methods, particularly where the voice of the pupils themselves is sought and heard, need to be considered.

Research involving structured interviews with disabled children (Rackett, 2002; Allcock *et al.*, 2002) has suggested that whilst special schools provided pupils with a safe environment within which to develop their identity and sense of self, this was at a cost of being isolated from the able-bodied world; whilst those attending an integrated or resourced school (i.e. those mainstream schools given additional resources, usually for an identified group of children) displayed the greatest amount of assertiveness and ambivalence about their place in the world. Pupils who attended mainstream secondary schools which were not specifically resourced lay somewhere in between, expressing highly individual experiences, but with a definite reference to the need to have “a protective shell” (Rackett, 2002, p. 56). The picture of social acceptance characteristic within special schools and featured in integrated provision was missing here and instead a

feeling of persecution pervaded the responses. Rackett suggests that this might be the result of the pupils not having enough other people with disabilities around them.

Studies which have examined the social adjustment and self concept of students who attend special classes compared with students who attend ordinary classes have generally reported conflicting results, with either no significant differences, or differences favouring one group or the other (Vlachou, 1997). She argues that such studies are futile and problematic when the debate is concerned with the integration versus segregation processes, since they assume that the development of self-concept or self-esteem and the concept of 'social adjustment' are context-free processes, rather than the sense of self being a product of a person's interaction with others. In addition, she points out that these studies often attempted to quantify the complex processes of the development of self identity through the use of a rating scale of self-esteem. She emphasises the need to consider the whole experience of the disabled person in their context, and to consider the experience of inclusion in the generic educational community. Other writers have emphasised the need to explore the meaning of inclusion from the viewpoint of disabled people themselves, those who have experienced segregated education and those who have strived to be included (Cook *et al.*, 2001; Leicester, 1999).

Studies which have employed ethnographic methods to access the experiences and views of the children and young people themselves have found that disabled children report problems with inclusion in both mainstream and special school settings:

“It is our belief that those who argue for the existence of special schools on the grounds that they prevent disabled children from being harmed by other children or adults are deluding themselves, because we have found that the same oppressive processes are to be found in both types of schooling” (Davis and Watson, 2001, p. 685).

The present study has been conducted from the perspective that disabled children have a right to full engagement and participation in mainstream schools, and a belief that there is a need for further research into their views and experiences to contribute to processes and discussions at school, LA and national level, that develop and improve inclusive education.

1.9 Research with Young People

As adult researchers we attempt to report on or speak for others which raises ethical issues for the conduct of our research. This becomes even more problematic for children because of the imbalance of power relations and the differences between adults and children.

Matthews (2001), looking at ethical (power) issues when adults work with children and young people, emphasises that we need to be clear how our preconceptions or misconceptions might colour our interpretations of events and experiences. However, the understanding gained in a sensitive and ethical way is better than saying such study is out of our reach, since this would be just “an excuse for maintaining the hegemony of adulthood” (Matthew and Limb, 1999, quoted on p. 118). We need to consider the balance of power in the research relationship, to seek the active involvement of children and to take the children’s own views and feelings about their lives seriously, all of which has not been previously done by researchers and academics to any great extent (Corsaro, 1997; King, 1996). Doing this is a key focus of the present study.

I will now consider research that has been conducted *with* young people, rather than on them. The importance of research *with* children and young people has increasingly begun to be highlighted by a number of writers.

“Inclusion of and engagement with the perspectives of research participants can enhance the claims of empirical researchEngagement between researchers, participants and stakeholders is a crucial part of the research process” (Fraser, 2004, pp. 16-17).

Here, ‘empirical research’ is defined as involving a ‘systematic investigation of experience’, that it should be ‘sceptical’ and that it should be ‘ethical’ (Robson, 2002). It accepts that our experience of the world can be a valid way of deriving new knowledge. Fraser (2004) talks about techniques which might be termed ‘child friendly’, suggesting that these will be used and understood differently according to the context and they will be dependent on the cultural frames of reference of the researcher and the participants. The degree of reliability and validity of such methods will be related to the degree of shared understanding of the research between researcher and the researched. These techniques may be viewed as ‘participant friendly’ rather than ‘child friendly’. What is important is a

positive engagement with children and young people as a necessary precursor to the credibility of the knowledge derived from research.

Issues such as access, consent, ethics and power relations will all affect the outcomes of research (Lewis, 2002). The theoretical and methodological approach taken will influence the research outcome. Since the reasons for conducting research with children and young people are to understand them better, to improve their lives and to ensure that the research is effective and appropriate to these ends, then it is crucial that researchers engage *with* children and young people and negotiate the nature of the research with them, by empowering their participation and informed consent.

1.10 Voice of the pupil

The United Nations Convention on the Rights of the Child (1989) gives children the right to express their views and have them heard about issues which affect them. The United Kingdom ratified the convention in 1991, yet there is very little evidence of any action taken to ensure its implementation (Franklin and Franklin, 1996). Over recent years attention to pupil participation is increasing in the education system, and this is illustrated by the Government's agenda for education. Children's participation has a dedicated action plan (DfES, 2002) and is part of *Every Child Matters* (DfES, 2003). In November 2008 legislation placed a duty on all maintained schools in England and Wales to seek and consider the views of its pupils on matters affecting their education and school life (the new Section 29A of the Education Act, 2002, CRAE, 2008) and there are government promoted initiatives such as Hear by Right (the National Youth Agency) and Participation Works to support participation and the active involvement of children and young people in relevant organisations.

May (2005) questions whether this current emphasis on pupil participation is really about hearing the pupil voice and making the pupil an active agent, since it is directed at the role of the adult in bringing about such participation. She suggests that there should be greater exploration of pupil participation from the perspective of the pupils themselves and more balanced active roles between both pupils and professionals. Other researchers are calling

for ‘greater critical scrutiny and rigour in terms of some of the rhetoric used and just how it relates to practice’ (Wood, 2010, p. 1).

There have been constraints on the development of pupil participation and seeking pupil perspectives, due to perceptions of ‘progressivism’ driven by political influences together with public perceptions of childhood that have made it difficult for people to take seriously the idea that young people can contribute to debates and decisions which affect them (Rudduck and Flutter, 2000; Shelvin and Rose, 2008). Detailed considerations at many levels should be made if students are to be given a genuine voice in how education is delivered and received – the pragmatic level of who is allowed to speak, who is listening, how the skills of dialogue are taught, how are supportive and facilitative attitudes fostered, moving onto systemic and organisational thinking which contrasts performance-led listening with person-centred education (Fielding, 2001). This will involve drawing together research from a number of disciplines including cognitive science and child development (how to engage learners), sociology (power relations in schools), civic rights and citizenship education (giving pupils the skills they need to participate), in order to make substantial progress on this agenda (Johnson, 2004).

Recent work on child wellness and inclusion has emphasised the importance of equipping the child with adequate skills to participate meaningfully in society (Prilleltensky, 2010); he describes Participatory Action Research (PAR) as a methodology to achieve that goal. He cites several researchers who are concentrating on the need to create competent young researchers who can get to root causes of problems, carry out research and demand action from local government, using methods such as photovoice and other innovative ethnographic techniques.

Involvement of children in the research process, that is children as researchers, rather than research with children, where children carry out research with their peers or around their own situations, would help address power imbalances, encourage intimacy, fuller discussions and better understanding and follow a respects and rights agenda (Alderson, 2001). Alderson describes three levels of involvement of children in research, ranging from the child carrying out activities which are of interest to adults, whilst practising research

skills to research being mainly initiated and directed by the children and teenagers themselves. Children might be involved at different if not all stages of the research process – initial planning and design, central collecting, reporting and analysing of data, and at the follow-up, writing and publishing stage. Children often get better response rates and more access than adults would in similar circumstances and the outcomes of research are more powerful and meaningful as a result (Alderson, 2001).

Hart (1997) describes eight levels of children's involvement in research as eight rungs of a ladder, leading to increased involvement and autonomy, ranging from manipulation, decoration, and tokenism as the bottom three rungs, to the project initiated and directed by children at the top. In the present study, I felt it was important to avoid exploitation or manipulation of the children and really 'hear' what they were saying, particularly if it feels threatening to the adults or school organisation I am working with. As I was a visiting professional to the school (outsider) in the present study, rather than a member of staff in the school (insider – see Hellowell, 2006, discussed below in section 1.12) it would have been difficult for me to facilitate a project at the top rung of the ladder, though this would allow more flexibility and opportunity within the curriculum to enable the children to plan, design and carry out their own research and monitor and support them through the process. However this study addressed the fifth rung of the ladder 'children being consulted and informed' and to some extent the sixth rung 'adults initiating but also sharing decisions with children' by consulting and sharing decisions with children and in this way making sure their voice was heard.

1.11 Consulting with disabled young people

Foremost in this work is the need to consult and listen to children's narratives. Disabled children are historically an unheard, powerless group, being both children and disabled, and an important initial step on the journey to participation and voice is to consult with them about their experience. Researchers working with a range of marginalised groups have stressed that this should move beyond mere tokenism to a genuine desire to listen and reflect on the opinions given (Rose and Shelvin, 2004; Wilson, 2004).

Researchers have used a range of methods to facilitate consultation with children. Age appropriate methods have been explored to facilitate the collection of perspectives from younger children (e.g. the 'Mosaic' approach, Clark, 2004; use of activity based interview formats, Ravet, 2007), whilst other researchers have adopted ethnographic methods, working through teachers presenting curriculum based topics to access pupil views (e.g. Rassool's (2004) investigation of the issues of race and gender for immigrant pupils). Other studies seeking the views of disabled children have used a variety of methods, also depending on the age and functional abilities of the children. These include (participant) observation in school settings, drawings, spidergrams, sentence completion tasks, (postal) questionnaires, focus groups and (semi-)structured interviews or 'structured conversations' with the children, often in the presence of parents, carers or teachers, who may also be interviewed (MacArthur *et al.*, 2007; Lightfoot *et al.*, 1999; Woolfson *et al.*, 2007; Davis and Watson, 2001; Watson *et al.*, 2000; Skar, 2003; Connors and Stalker, 2007). However, working through other adults, such as parents or teachers, raises ethical issues such as whether the children are giving informed consent and ongoing assent and really understand what information the researcher is collecting from them and how they intend to use this, i.e. issues of ownership and control. In addition it may be more relevant to address the issues of importance more directly rather than by 'devious', indirect methods, particularly with older pupils who can be questioned directly. These studies also report a loss of data, for example when there is a reliance on others making tape recordings or keeping work samples (Rassool, 2004). Interview studies involving more direct questioning are reliant on the relationship between the researcher and the child, and require there to be rapport and shared understanding. For example Ince (2004) comments on the importance of the impact of a black researcher interviewing black care leavers (p. 228) and in the present study, the involvement of a disabled researcher was felt to be a unique aspect of the research, which would facilitate the pupils to share their views and experiences of school.

1.12 Working with disabled pupils

Some of the issues regarding defining 'disabled people' as a distinct social group have been discussed above where the social model would formulate disability as a structural relationship between people with impairment and a discriminating society. Such a conceptualisation offers insight into the collectivity of the disability experience but should not obscure real differences between disabled people which include gender, race, sexuality and social status. A balance is needed between recognising the commonalities and respecting the differences (Shakespeare and Watson, 1998).

Similarly, the new sociology of childhood (Corsaro, 1997), promotes a view of childhood as a social construction, and advocates looking at the child's experiences in different social contexts and the child's 'agency' in shaping these social contexts. This includes collecting disabled children's views and experiences and requires challenging discourses of disabled children as a passive, vulnerable, homogeneous, separate group. Evidence emerging from recent studies promoting this approach suggests that disabled children want to be seen to be 'like other children' (e.g. Watson *et al.*, 2000) and there are other things than disability influencing their lives such as poverty, gender and personality.

Moving on from the exploration of the development of models of conceptualising disability it is possible to establish principles to think about when conducting research with disabled children. Shakespeare and Watson (1998) suggest three such principles: the principle of equality and entitlement; the principle of inclusion, where services are planned with everyone's needs in mind; and the principle of autonomy – service providers should adequately consult with disabled people, who should themselves set the agenda, dictate the priorities and have a real voice in decision making about their lives. These principles provide useful criteria to consider when discussing children's experiences of school.

Beresford (1997) points out that the "social relations of research production" (Oliver, 1992, p. 106) also need to change:

"This will require greater dialogue between researcher and disabled people throughout the entire research process, beginning with the identification of key issues, through the development of a research question, formulating the research design, collecting and interpreting the data, to, finally, the ownership and dissemination of the research findings (Oliver, 1992; Barnes, 1992)" p. 18.

Beresford argues for the use of qualitative methods such as individual interviews and group discussions and using these to inform the development of large scale measurements such as questionnaires, where these are needed. This will increase face validity, appeal and salience to respondents.

Shakespeare and Watson (1998) identify three problems with existing literature about disabled childhood. First it is usually non disabled people discussing disabled people; second it is adults discussing children; and third the definition of disability is a problem

within an individualistic and medicalised model. They state, “Listen to what disabled children say about their lives, respect their wishes and support their choices” p. 26. This underlines a crucial aspect of the present study where engagement of the pupils who are the focus of the research and consideration of the power relationship between them and myself as a disabled researcher are important issues, particularly when considering the methodological aspects of the study.

A key area for the reflective researcher is to consider their ‘insider/outsider’ status in the research arena (Hellowell, 2006). Whilst insider research may lead to unchallenged ‘taken for granted assumptions’ (Hockey, 1993, p. 199), at the other end of the continuum there are issues regarding how the ‘strange’ world (Schutz, 1976) is accessed and experienced by outsider researchers, in order to make it intelligible. In the present study, this relates to a number of different aspects, e.g. familiarity with the school setting (Eisner, 1997); being disabled or not (Oliver and Barnes, 1997); being an adult researching the viewpoints of children (Davis, 1998); even being a woman interviewing adolescent boys – gender contrasts (e.g. Smith, 1994). Instead of viewing the insider/outsider researcher status as one of absolutes, it is useful to think of this status as involving a number of different aspects each of which can be regarded on a continuum, “which encourages researchers to explore to what degree they can be called native or stranger and – through this awareness - to utilise the best aspects of both roles to inform and enhance their research experience” (Le Gallais, 2003, p. 2). In this study I had multiple constructed identities which I was able to use as a ‘tool’. In some respects I was an ‘insider’ in that I had been the named educational psychologist for the school for several years and as such was a high status professional who was considered to be part of the adult team. This clearly helped me to gain access into the school in order to invite the children to participate in the research. At other schools, where I did not have this professional support role giving me insider status, I was not able to gain access to initiate the research. In addition I am a disabled person who is a wheelchair user and I felt this increased my insider status with the young people by granting me some shared empathy and experience with the pupils themselves. On the other hand I could be classed as an outsider being a visitor to the school rather than a constant member of staff, a woman rather than an adolescent boy and also having an acquired disability and therefore not having attended school as a disabled child. In these respects the participants became the experts and the power relations between us change – their voice became dominant as I went out of my way to make them feel valued and heard. However, I was still an academic researcher with my own expectations and requirements which placed me in a position of authority and control and the interpretations placed on views expressed

by the pupils were inevitably mine. (See chapter 3 for a discussion of the ethical issues raised here and how they were addressed in the formulation and conduct of this study).

I will now move on to consider findings regarding the experience of mainstream school from research that has been conducted *with* disabled children.

1.13 The experience of disabled pupils in mainstream schools

A review of the literature on disability discrimination in education across the 0 to 19 age range by Gray (2002) suggested that there were few examples of large scale studies and those studies that did exist, were often focused on people who had left education and were considering their experiences retrospectively. Whilst there was some evidence of reported incidents of extreme prejudice and discrimination towards disabled young people in educational settings, most discrimination was more subtle and often unintended, with attitudes of pity leading to low expectations of their future contribution to society amongst education staff and young disabled people themselves. These discriminatory attitudes developed across the course of schooling and were not present at an early age. Geographical distance and peer group restrictions were found to inhibit the development of disabled pupils' social lives and leisure opportunities. Positive attitudes amongst non-disabled adults and peers were generally developed through direct experience, rather than just awareness raising and more positive attitudes were noted in inclusive schools (Gray, 2002; Wilson, 2004).

More account still needs to be taken in research informing educational policy and practice of young disabled people's perspectives and experiences. There have been a number of studies which have attempted to hear the viewpoint of disabled children and young people (e.g. Cook *et al.*, 2001; Davis and Watson, 2001; Shaw, 1998; Beresford, 1997; Lewis *et al.*, 2006; Connors and Stalker, 2007; MacArthur *et al.*, 2007). Children themselves should be enabled to challenge conditions in schools which 'create' disability (Davis and Watson, 2001). Cook *et al.*, (2001) explore the meaning of 'inclusion' from the viewpoint of disabled people who have experienced segregated education. Their observations underline the abusive situation of disabled pupils who were not consulted about segregation, and then not involved in the discussions/consultations leading to a return to mainstream.

A number of recent studies have sought the views and experiences of disabled pupils across a variety of settings, engaging simultaneously with new approaches to the study of disability and new approaches to the study of childhood. A major study was carried out

between 1997 and 1999, involving 7 researchers, in 14 schools, including both mainstream and special schools in England and Scotland, and involving some 300 children aged between 11 and 16 years (Watson *et al.*, 2000). The study used ethnographic approaches where the researchers became participant observers, and also conducted interviews and conversations with individuals and groups of the children. They identified four main themes from their observations and analysis: the high degree of surveillance by adults which was experienced by the disabled children, which affected their privacy and influenced their relationships with non-disabled peers and which was actively resisted by some of the children; the creation of the disability category by the social structures and adult discourses which surrounded the children, whilst the children themselves were more ambivalent about the use of this category; limited relationships with peers due to physical, attitudinal and communication barriers; and the fluidity of the young people's identification with disability (i.e. they did not always see themselves as disabled in every situation) compared to the tendency of adults to give primary emphasis to disability when dealing with them. The outcomes of the study challenged the view of a universal concept of 'the disabled child' and instead identified how adult discourses and values were reinforced through daily institutional practices. The researchers conclude that young people are the experts on their lives and the adults working with them should reflect on their own practice, and be prepared to consult with the young people and learn from them.

1.13.1 Difference

Subsequent papers from this research have explored these issues in more depth. Davis and Watson (2001) analyse more closely how the adults and teachers labelled and defined the children as different in both the mainstream and the special school settings. At the same time these adults wish for them to be 'normal' and so the children are measured against physical and cognitive norms and the adults aim to correct their abnormalities. There was also a narrative of dependency on non-disabled people, both adults and other pupils, a discourse of charity and reliance on others. However there are also examples of children resisting these adult interpretations and not passively accepting adult discourses concerning normality, though it appeared that the children's perceptions and solutions were often ignored, with a continuing emphasis by the adults on within child factors rather than any fault lying with the teacher or the peer group. The authors suggest that there is a need to address group cultures, rather than concentrating on changing individuals, e.g. in bullying situations where individual is perceived as 'not normal'.

Structural issues within schools, such as the creation of ‘units’, or resourced provision, can create segregation and difference and combined with the adults’ discourses, can limit the educational opportunities of disabled children – teachers can be unaware that their beliefs about the world may influence their perception of different children (Davis and Watson, 2001). Whilst often children resisted the discourses created by the adults – sometimes they drew from the adults’ discourses of differentiation to label each other. Streaming creates physical distance between pupils, and this is sometimes used by the children to meet their own ends, e.g. to have an easy time and underachieve or as an opportunity to opt out (Davis and Watson, 2001). At times children are aware of being overprotected, often because of a fear of litigation on the part of the adult; safety issues are often used to reinforce segregation or lack of involvement of disabled pupil (for example, when a pupil cannot join in a PE activity).

Other ethnographic studies have also noted this awareness of ‘difference’ in the children observed. MacArthur *et al.*, (2007) report a study of seven 11-14 year old disabled children in New Zealand, focusing “on their agency as they negotiate a complex, changing, and often challenging social world at school where ‘difference’ was experienced in negative ways” p. 99. The paper draws on ethnographic data from a wider 3 year study looking at the influence of school experiences on both disabled and non-disabled children’s identity as they make the transition from primary to secondary school in regular New Zealand schools, focusing specifically on the experiences of disabled children (though it is not clear what their impairments were). They conclude that:

“It is clear that children have a growing awareness of difference in comparison with their non-disabled peers, and their perceptions suggest that they are walking a tightrope between wanting others not to view them as different, yet feeling different and being treated differently, particularly in negative ways” p. 105.

These differences may be due to their impairments (Morris, 1991; Thomas, 1999; Lightfoot *et al.*, 1999), but recent studies, where the researchers emphasise a social model approach, are indicating that other contextual elements surrounding the children reinforce these perceptions (cultural and structural aspects of the school setting, discourses of adults, relationships with peers - Connors and Stalker, 2007; MacArthur *et al.*, 2007; Davis and Watson, 2001). This suggests that medical model thinking is still very much underlying the perceptions and discourses used within these educational settings, where the disabled

children and their impairments are seen to be the problem rather than the social or even affirmative models steering the children's experiences, where the child is equally valued and the 'problem' belongs to the setting.

In these studies most of the children were positive about school (MacArthur *et al.*, 2007; Connors and Stalker, 2003, 2007; Watson *et al.*, 2000). They report examples of disabled children taking action to resist situations they did not like such as bullying, sometimes inappropriately through using inappropriate language or actions, but certainly taking the initiative. There are also positive examples of disabled children taking action, such as talking to their peer group to explain their impairment and its impact, to enhance their acceptance with peers and sense of belonging in the classroom.

Connors and Stalker (2007) also identify 'difference' as one of four ways disabled children in their study experience disability. In addition they found significance for 'impairment' and its effects; other people's reactions which create 'barriers to being' (Thomas, 1999) and material barriers, such as lack of access, transport difficulties and lack of support with communication. They carried out several 'guided conversations' with 26 disabled children aged between 7 and 15 years, in their own homes using a variety of child-centred methods. There was a range of impairments represented, with over half of the children having learning difficulties and 6 with physical impairments. One off interviews were also conducted with 24 siblings and 38 parents. They noticed that the disabled children's responses regarding problems were very different from those of the parents, with the children being generally positive about their lives whilst identifying problems of immediate relevance, such as boredom experienced at home, with a lack of socialising opportunities with their peer group, whilst parents reported instances when the child had been discriminated against or treated badly. In addition, whilst parents thought that their children were aware of their differences to other children, most of the disabled children did not mention this and instead, focused on their sameness. This underlines the importance of seeking the views of children directly from them, rather than relying on reports from the direct contact adults, who have different perspectives.

Connors and Stalker (2007) offer several possible explanations for this focus on 'sameness' by the disabled children: that they are minimizing or denying their differences; that the children are active agents resisting disabling barriers and attitudes and showing their perception that their impairments and disability are not the defining features of their identity; or, the authors' preferred explanation, that the children did not have adequate

language or concepts to discuss their differences. It is possible that all these explanations and others (for example ‘difference’ is not viewed positively and is therefore resisted) may have a role to play, to different degrees for different children, due to the acknowledged heterogeneity of the disabled children and variance in their understanding and viewpoints dependent on such factors as their age, ability and experience.

1.13.2 Adult support

Another area of relevance to the experience of disabled children at school is their relationships with the adults who support them, particularly in mainstream settings. A number of studies have looked at the impact of adult assistants on the children they support (Lightfoot *et al.*, 1999; Watson *et al.*, 2000; Skar and Tamm, 2001, Skar, 2003). A high degree of surveillance by adults is experienced by disabled children and young people, who frequently mention their need for privacy and the detrimental effects of the presence of adult assistants on their relationships with their peers:

“There was little or no privacy for the children to talk. Teachers also commonly talked about the children as if they were not there, openly discussing the children’s medical conditions or what they understood about their home life in front of other children. As one child told us: ‘It may be hard to believe, but even I have things I want to keep private’” (Watson *et al.*, 2000, pp. 12-13).

Some disabled children resist this surveillance at times and attempt to assert their own autonomy and independence (Watson *et al.*, 2000). Complex and ambivalent relationships with assistants are reported with the most successful relationships being those based on a ‘professional’ role (Skar and Tamm, 2001). The ideal assistant described by the children was usually below the age of 25 years, same sex, and someone who facilitates independence and autonomy in the student. The children wanted to choose their own assistant based on their criteria of trust, strength, to be there only when needed, kind and cheery, with a reciprocated friendship role, though this latter was reported by the authors as particularly difficult to maintain, especially when the adult is supporting the child in social settings both in and out of school (Skar and Tamm, 2001; Skar, 2003). There is a need for mutual respect in the relationship with the support assistant for it to be successful and continuity is preferred, unless the relationship is not working, then this becomes frustrating. It has also been noted that disabled pupils can have virtually no relationship

with teachers, because of the presence of the assistants, and one study even reports that the pupils felt that they were being ignored by the teachers as an expression of contempt (Skar, 2003).

1.13.3 Friendship with peers

Research seeking the views of children and young people has shown that friendship is of great significance to them, particular in their experience of school.

“When children are asked about the things that are important in their experience of education one factor appears to be important above all others – friendship. In a study of 2,527 children in 500 primary and secondary schools in one local education authority (LEA) in the north-west of England 62.8 per cent stated that happiness at school was the result of friendships (Whittaker, Kenworthy and Crabtree, 1998). This included best friends and also friendly teachers and other friendly pupils. Along with this, ‘feeling safe, making other children happy and being trusted by others’ also added to their happiness (Whittaker *et al*, 1998). ...When asked about what makes them unhappy the most commonly cited factor was bullying, either directly of themselves or of others within the school. ” (The Open University, 2004)

Friendships can provide a supportive and protective function for psychological health whilst negative relations with friends is inversely related to mental health and can lead to a decline in mental health over time (Helgeson *et al.*, 2007).

Skar and Tamm (2001) and Skar (2003) draw on Bronfenbrenner’s (1979) developmental theory to suggest that the roles and relationships children have and the activities they participate in are important factors in their development. Children should develop multiple roles in their interactions with others and if roles are limited, they suggest that this can impede development. Relationships with peers are seen as particularly important, particularly in the development of identity – if the child relates mostly to adults this reinforces dependency (Skar, 2003), rather than the independence required amongst peers. Disabled adolescents are found to have significantly lower social integration and participation in activities and social environments, reportedly through the low accessibility of environments, limited stamina, physical pain as well as perceived restrictions due to being seen as different because of their impairment (Skar, 2003).

From junior age to early adulthood use of social leisure for children and young people shifts from organized leisure clubs and activities run by adults to more casual leisure where young people hang around in groups or visit each others homes, to 'commercial' leisure where the young people visit pubs, clubs and cinemas (Hendry *et al.*, 1993, Skar, 2003). Participation in social leisure time has important developmental consequences in promoting social competence and community contacts, reducing isolation, and developing a positive self-image, for disabled children and young people as well (Cavet, 1998). However disabled young people have more limited opportunities for leisure activities outside their own homes and beyond their families (Hirst and Baldwin, 1994). The relative poverty of disabled people and their families also affect availability of appropriate transport, plus extra costs of activities associated with disability (Shakespeare, 2000). Transport was exempt from the Disability Discrimination Act in 1995, until 2005 when campaigning by the Disability Rights Commission led to new regulations being introduced requiring all new land based public transport vehicles to be accessible to disabled people (this was enforced in 2006). Hence, the availability of accessible transport is still a very significant issue, and it will be a number of years before accessible transport is available universally, and even then, it will be limited on occasions, for example, in rural communities, where frequent services are not cost effective to the private sector which runs the service. In addition unsuitable physical outdoor environments, even in town centres, makes independent travel very difficult for disabled people.

Leisure options for all young people are constrained by cost and availability and this is compounded for disabled young people when transport, access and material issues are taken into account (Hirst and Baldwin, 1994).

Studies seeking the views of disabled pupils confirm these restrictions in school settings too. Pupils with impairments and chronic health conditions report losing break times on treatment or personal care tasks; after school activities affected by tiredness, inability to participate physically, feeling self-conscious, needing to go home on prearranged transport and school trips missed because of illness or lack of adult support (Lightfoot *et al.*, 1999). They found that over a third of the young people with an illness or 'disability' in their study felt that they experienced difficulties at school with peer relations because of it, such as unwelcome peer curiosity, being ignored or experiencing bullying. Some found friends to be very supportive and felt that they reciprocated this. The pupils appreciated having friends with them when reasonable adjustments were made, for instance, when leaving the classroom early to avoid busy corridors.

Use of the internet and online social networking sites may offer some enhanced social leisure pursuits for young people (Clarke, 2009), though again material barriers at present affect the availability of suitably adapted, accessible equipment for impoverished disabled children and their families at home.

There are specialist leisure facilities or groups available to support disabled children and young people (e.g. the Phab charity), though use of these has been questioned, because of their potential to reinforce social exclusion and devalue friendship with disabled people, although it can be argued that meeting with other disabled people can provide opportunities for mutual support and friendship, e.g. deaf clubs (Lightfoot *et al.*, 1999). These researchers suggest that real choice needs to be available to the disabled young people, with both options available.

1.14 Conclusions

It can be seen from the above literature review that there is a wide range of issues which can impact on the understanding and interpretation of the experience of disabled children in mainstream schools today: from evolving historical perceptions of disability, including the models of disability espoused by researchers and practitioners; the legislative background of the growth and development of educational provision for these young people; the research approach and methodology espoused when investigating inclusion and the engagement of the young people in this process and the discourses used to evaluate inclusive practice and who provides these, whether it be parents, teachers and school, LAs or the pupils themselves. Inclusion can be viewed as an issue of rights (Sheehy *et al.*, 2005), expediency (Education Act, 1981) or efficacy (Lindsay, 2003), depending on which perspective is considered. The current research is situated within a 'rights' agenda – disabled people, including children, have an equal right to participation, choice and empowerment and a right to have their views sought and taken into consideration within the provision that is made for them (Barton, 1995; Oliver, 1995; Beresford, 1997). Seeking the views of the disabled pupils themselves and the implications of this for the research agenda and methodology used has been explored and the principles of equality and entitlement, inclusion, and autonomy (Shakespeare and Watson, 1998) outlined. This research aims to contribute to the current need to find out from disabled pupils what school is like for them, using an approach aimed to facilitate their participation.

A number of key issues have also been identified with regard to the existing research literature on the experience of disabled children in mainstream schools. These include the

unreliability of ‘outcome’ studies; the need to consider the whole experience of the disabled person in their context and from their viewpoint; growing awareness of adult discourses of difference emphasised in schools by streaming, the creation of ‘units’ and other contextual elements; the mostly positive outlook of disabled children about school, where they want to be seen as the same as their non-disabled peers and the high degree of surveillance they experience, particularly from the adults who support them. Self-identity research suggests that disabled young people do not have less favourable self-perceptions – there is evidence emerging that the perception of self as disabled and the negative connotations this implies may be created and reinforced by the context set by adults, though disabled young people do express an awareness that this is how they are seen by others because of their impairments (Watson, 2002; Skar, 2003). In addition, the overwhelming significance of friendship and social contact with their peers for children and young people has been noted.

1.15 Research Questions

This research focuses on exploring the significant experiences of disabled pupils who attend a mainstream secondary school with resourced provision provided by the local authority to ‘meet their needs’ as assessed by the local authority under the Education Act 1996. Fundamentally the research seeks to collect and reflect on these experiences as they are described by the pupils themselves. My research questions are as follows:

1. How can my approach to this research promote the engagement of the participants and ensure their views are heard?

I will consider and address relevant ethical and methodological issues to try to ensure that the disabled pupils experience this research as relevant to their needs and where their views are recognised as important and significant (Chapters 2 and 3).

2. What are the children’s experiences of being a disabled pupil in the school?

This research will focus on providing the participants with the opportunity to describe their experience of being a disabled pupil in the school, to a listening adult who wants to find out what school is like for them (Chapter 4).

3. How do these pupils perceive themselves and how do they express this in their self-descriptions and reflections on their experiences at school?

I will consider issues of self-identity for these pupils as reflected in what they tell me about their experiences at school and their perceptions of these (Chapter 5, section 5.3).

4. What issues do these views raise for educationalists, practitioners and policy makers working towards inclusion?

This research will look at the implications of the views of these disabled pupils for inclusive policy and practice (Chapter 5, section 5.4).

Chapter 2: METHODOLOGY AND METHODS

2.1 Introduction

My chosen methodology and methods were determined by my first research question. A social constructivist analytical framework was adopted in this research and central to this is a focus on lived experience of the world as it is felt and understood by social actors (Schwandt, 2000). Reality is seen to be created through the process of social exchange, historically situated. This qualitative approach rejected the naïve realism of positivist approaches, in favour of a relativism based on multiple mental constructions formulated by groups and individuals (Guba and Lincoln, 1994). In contrast to a positivist approach a qualitative approach does not seek a reality or ‘truth’ but accepts that all interpretations are enacted by the researcher and are time limited, provisional and historically embedded.

“Theories are interpretations made from given perspectives as adopted or researched by researchers” (Strauss and Corbin, 1994, p. 279).

An interpretation or theory is therefore fallible; however judgements can be made about its validity and usefulness by reference to the data on which the interpretation is grounded.

The grounded theory approach to analysis helps to identify underlying structures and mechanisms whilst generating theory from the data itself (Glaser and Strauss, 1967). The approach as propounded by Strauss (1987) has been challenged by some researchers who suggest that it attempts to adhere to the guidelines of positivist approaches (Denzin, 1988; Thomas and James, 2006), using terms such as theory, hypotheses, concept, validity, reliability. Post-positivist stances argue that whilst not denying the value of interpretative, constructivist and relativist views, there is still virtue in maintaining a broad scientific approach to real world enquiry (Robson, 2002).

Generalisability, as derived by quantitative methods, that is to produce ‘laws’, is a concept which, it can be argued, is at odds with qualitative approaches per se (see Schofield, 1990). The participants chosen for this research offered a valid insight into their experience as disabled children educated in a mainstream setting which for most of them was ‘special’ in that it was not their local neighbourhood school, and in nearly all cases had involved a new beginning for them in terms of peer group, locality and community. The expression of these experiences by these pupils will help to inform issues to be considered in determining and delivering educational provision in a local authority setting. The analysis of the data

and the analytical approach followed works towards the validity of the outcomes of the study, rather than a statistical approach more familiar in positivist methodology.

2.2 Research methods and rationale

This research aimed to give a voice to the views of disabled pupils who attended a resourced mainstream secondary school. The approach taken aimed to confront previous claims that disability research is experienced by disabled people as alienating by ensuring that the methodology used sought the informed involvement of the disabled pupils, being relevant to their needs and aiming to improve their circumstances and experiences of life (Oliver, 1992; Morris, 1992). Thus it needed to ensure that the pupils felt comfortable and motivated to participate in the research and that the messages that they wished to convey were heard and carried forward. In order to investigate these questions, a qualitative, or 'interpretative' approach was taken where "disability is...a social construction of multiple experiences waiting to be recognized" (Ferguson *et al.*, 1992, p. 296). The researcher aimed to learn as much as possible about the interpretations and perceptions of the pupils and these then became absorbed into the researcher's own interpretations and conceptualizations (Strauss and Corbin, 1994).

In order to maximise the involvement and expression of the views of the pupils themselves it was felt important to find a method which was led by what they had to say. A questionnaire or structured interview approach, whilst allowing for more pupils to respond, would limit the range of possible responses and would require the researcher to set the agenda in predetermining the questions before the pupil responded. For the purposes of the current study it was essential that the views of the disabled pupils were expressed in their terms, although some structure was necessary to ensure that the focus remained on their experiences in school. Therefore semi-structured individual interviews were used to ask the pupils about their social and academic experiences in school, to seek their views of their friendships and the support they received and to consider the statements they made about these experiences (Hammersley and Atkinson, 1995). The approach and methodology used was chosen to engage the pupils throughout the research agenda, to ascertain that they fully understood the purpose and aims of the research, to ensure that informed consent was given and that the pupils understood that they could cease their involvement at any time.

A number of previous studies did not ask the disabled children directly about the experience of being disabled, but derived their interpretations from what they observed or how the children responded. For example, Connors and Stalker (2007):

“We did not include direct questions about impairment in the children’s interview schedules, nor did we think it appropriate to ask the children, in so many words, how they ‘understood’ disability’. Rather, we preferred to wait and see what they had to say on these topics while telling us about their daily lives generally and in response to specific questions” (p. 22-23).

In the present study, as a disabled researcher talking to disabled children it was felt to be unnecessary to avoid asking direct questions about the children’s experience of being a disabled child at school and this aim of the research was shared with the children at the start of the process to inform their decision whether to participate. The children were all able to respond verbally in an interview setting, and would have had greater difficulties accessing other media involving, for example, drawing, operating recording equipment or reading, because of fine motor co-ordination difficulties or associated learning difficulties. In addition, to access activities requiring physical manipulation would have required the presence of an additional adult or non-disabled peer, since I would have been unable to help them, given my own physical limitations. This would not have achieved my aim, as the researcher, to allow the disabled child his or her own confidential space to share their valued, personal views, and there would have been a danger of the researcher ‘studying down’ (Thorne, 2004, p. 254), assuming that such techniques are necessary with adolescents, when these young people are capable of expressing their own views verbally, if the adult is prepared to suspend their preconceptions and listen to them. The interviews were videotaped, to ensure that they could subsequently be transcribed accurately, since some of the young people had speech impairments, and also, note could be taken of their body language and non-verbal communication.

2.2.1 Qualitative Interviewing

For this study the method of one to one interviewing was employed to access the views and perceptions of the pupils. I felt it was important that the interviews were semi-structured, in order to offer some support to the pupils in terms of guiding their thinking to issues connected with their experiences at school and within the community of school life. However, it was also important to allow the pupils to follow their own particular themes, to discuss those issues within this framework which were important to them. Stroh (2000) discusses this benefit of such qualitative interviewing in comparison to questionnaire studies:

“The tendency of questionnaire surveys to ask a rigid set of simple questions which ‘force’ or push the respondents answers into particular categories, which they may not have thought of unprompted or may not want to use, is just one of the reasons why researchers often choose to use interviews either as a supplement or as an alternative to a questionnaire survey” (Valentine, 1997, p. 110, quoted on p. 198).

Stroh claims that interviews therefore answer the ‘why’ questions rather than just the ‘how many’ or ‘how often’ questions. However it can be argued that semi-structured interviews still push respondents down certain paths by the areas they decided to investigate. Thus open-ended questions become very important as well as avoiding using leading questions when prompting or seeking clarification or elaboration. Interviews become a sensitive way of exploring meanings and understandings: “what qualitative research can offer is an understanding of people’s ‘life-worlds’, trying to understand situations from the perspectives of those being researched” (Stroh, 2000, p. 202). Interviews offer a sensitive way of exploring the meanings and understandings of the participants and as such give insights into their ‘life-worlds’ and perspectives. Smith (1996) describes this as adopting a ‘phenomenological perspective’ (he quotes Giorgi, 1995) or a ‘symbolic interactionist perspective’ (he quotes Denzin, 1995).

There is a need for ongoing reflection and self-awareness by the researcher throughout the interviewing process as there are ways this ‘conversation with a purpose’ (Burgess, 1991) might go wrong. The interviewer needs to be aware of power relations which are more fluid than within more structured approaches such as the use of questionnaires. The interviewer’s interjections can have an undesired effect on the interview and poor interviewing style can inhibit or end the conversation. Inappropriate or badly timed use of humour or sarcasm can interrupt the interviewee’s train of thought and stem the flow of data. Participants may come to feel they are being tested and it is important that participants are clear about the structure of the interview and that rapport and confidence are built (Stroh, 2000).

Semi-structured interviews were chosen as the method of data collection because they provided more flexibility than structured interviews or questionnaires, allowing spontaneity and follow-up of responses yet retaining some degree of standardisation (Hutchinson and Wilson, 1992). The use of semi-structured interviews allowed for

flexibility in the freedom to probe and to reword questions if the pupil had not understood what was being asked, or sought clarification. As Monteith (2004) states, “While reliability may have been somewhat reduced through loss of standardisation, the credibility and accuracy of the study were increased by ensuring that the young person understood the question being asked” (p. 168). Some of the pupils involved in the present study had associated learning difficulties and consideration had to be given to the practicalities of communicating with young people with learning difficulties. Monteith (2004) quotes a number of references, suggesting that the type of questioning used is an important consideration. Closed questions, requiring a yes/no response often tend to elicit affirmative answers which can invalidate the responses. Wyngaarden (1981) recommends that open-ended questions are used, which are simply phrased, with the interviewer having the freedom to reword questions, if the respondent appears not to have understood. The need to record the interviews, rather than the researcher taking notes, was also identified. Monteith (2004) cites Mattison (1970) as suggesting that interviews should be tape-recorded to reduce the levels of anxiety in the respondent associated with detailed note taking in interviews. In line with this recommendation the interviews were filmed, with the participants’ permission, and subsequently transcribed for analysis. The filming aided the transcribing by providing non-verbal gesture and expressions and visual cues, which were particularly helpful if the pupil had any speech or articulation difficulties, which several of these pupils had. However filming can be intrusive and clear permission and acceptance were sought from the participants, any of whom were able to ask for the recording to be stopped at any point. There were no such requests. Ethical guidelines for such interviewing were adhered to (Burgess, 1989; British Educational Research Association, 1992; Sheehy, 2005). (See Chapter 3 for further discussion of the ethical considerations in this study.)

2.2.2 Developing the interviewing strategy

Questions were selected and modified from those used by researchers in previous studies (Rackett, 2002; Hempstead, 1995), with particular emphasis on achieving open-ended, non-directive questions to encourage the pupils to explore and share their own experience, with only occasional closed questions as prompts to check understanding and preferences. A semi-structured interview schedule was devised which was further developed in trials where additional prompt questions were included to aid pupils’ understanding and to probe further if their responses were brief. In the interview pupils were asked about their experience of disability, about friendships, their academic experience at school, receiving support in lessons, and their plans for the future. At the end they were asked to comment on the process of the interview and if they were happy for what they had said to be used.

As the research progressed subsequent interviews included open ended questions reflecting emerging themes. (See Appendix 3 for the questions and prompts used).

In addition, in order to give their views pupils need to believe that they will be listened to, responded to and understood (Harris, 2003) and this was a key consideration in the present study. Children are in an educational system where their views are often not important and they are not always listened to. I made a point of listening carefully to the pupils I interviewed, using techniques of reflective, active listening (Rogers, 1965) to confirm with them that I was hearing what they were saying to me. It has been argued that the ‘core conditions’ of a counselling relationship (empathy, genuineness and warmth - Rogers, 1965) can be usefully applied in research interviews through employing active listening skills and open questioning, in addition to ongoing self-awareness of non-verbal communication and ‘effective attending’ (King, 1996). This was the style of interviewing I used with the aim of being individually enabling and engaging to the research participants:

“this mode of unstructured and responsive interviewing, when used reflexively, can enable especially the socially marginalised to be empowered because it assumes they can contribute significantly to the description and analysis of a social issue” (Opie, 1992, p. 64)

Consideration of establishing open channels of communication for the interviews was very important. I attempted to establish a relationship with the pupils to be interviewed, before the first interview, as a first step towards eliciting their views on the interview questions, by visiting them at school, to tell them about the research and seek their informed consent. I explained to the participating pupils that my intention was not just to hear their views, but also to respond to what had been heard by attempting to accurately represent these views and feed them back to policy makers and practitioners so that future practice becomes at least better informed and at best, improved to meet the needs of the pupils, as stated by themselves.

At the early stages of my interviewing I tried to maintain a standardised approach, whilst being adaptable to the context of the interview and the young person’s needs. As the interviews progressed I allowed the young people to talk about their own concerns within these areas, without hurrying to take them back to a ‘missed’ question or moving them on to the next question. I thus combined an interviewing strategy which was semi-structured with subsequent qualitative analysis which allowed me to

“capture the richness of the themes emerging from the respondent’s talk rather than reduce the responses to quantitative categories” (Smith, 1995, p. 9).

The data analysis did not involve preset codes, but explored perceptions, opinions and attitudes rather than testing out preconceived theories, hence a grounded approach was required where codes were allowed to emerge from the data (Glaser and Strauss, 1967), rather than being established before the research was conducted (Strauss, 1987). This grounded theory approach to analysis enabled me to relinquish some of my control over the progress and content of the semi-structured interviews and, instead to concentrate on encouraging the pupils to expand and explore their comments in more depth. I considered ways of involving the children more in the research process, and concluded that it would be difficult for me to achieve the highest level of pupil involvement and autonomy as described by Hart (1997) because I was, as a visiting professional, an outsider, rather than a member of staff in school (or insider - see Hellowell, 2006). My aim was to achieve consulting and sharing my interpretations with the children and in this way make sure their voice was heard.

2.3 Consideration of my own role in the study

Smith (1994) describes the use of a reflexive research focus which may be on the participant, the investigator or both. Another use of such reflexivity is to consider my own role as researcher, as a visiting professional and as a disabled adult who is a wheelchair user. Hellowell (2006) discusses the importance of doctoral students reflecting on their own position throughout the life of their research and the insights this gives to the interpretation of the information they collect. Such theoretical sensitivity on the part of the researcher involves considerations of which ‘self’ the researcher is prioritising at a particular time and place in the research process and how this is influencing interactions with participants, the data collected, the way the analysis is conducted and the interpretations emanating from the analysis (Cotterill and Letherby, 1994; Orland-Barak, 2002). This is an important aspect of the current research which addresses disability issues since it involved a disabled researcher, albeit an adult, and gave me the opportunity to reflect on my own position and how this was perceived by the disabled pupils.

As a disabled person I expected to share a sense of the experience of young disabled people, to some extent. However I did not share the experience of attending school as a disabled pupil, although I did have some empathy with the physical, social, emotional and

attitudinal barriers a disabled person might experience. I had visited the school many times before and met some of the pupils previously. For other pupils who had not met me before there may have been a different impact. I therefore included questions seeking views from the pupils I interviewed on the experience of talking with a disabled adult about these issues, during the debriefing part of the interview. I tried to be aware of my own attitudes and assumptions and the potential impact of my role and status on the engagement I had with the pupils whose experience I wished to explore. I also tried to be aware of the impact of these factors on the staff within the school with whom I tried to engage in open and full exchange of information and trust. I was aware of the need to adopt a reflexive approach throughout such qualitative research where my own attitudes and past experiences would impact on the data I collected and my subsequent analysis and interpretation and I have tried to make explicit the reasoning and influences underpinning my research (Tindall, 2001).

I was temporarily able-bodied (Shakespeare and Watson, 2001) until 25 years of age, when I had a car accident which resulted in a spinal cord injury and I became physically impaired, paralysed from the chest down, with limited hand function. I perceived that I had 'acquired' disability through my injury and subsequent physical limitations and it was up to me to overcome my difficulties (medical model thinking, World Health Organisation, WHO, 1980). I completed my training to become an educational psychologist, with the support of my husband, who gave up his job. It was necessary for him to do this if I wanted to continue to pursue my chosen career, because I needed to demonstrate to my employers that I was able to do the job, i.e. teaching and subsequently educational psychology. The barriers to this for me related to my personal care (toileting, dressing), managing equipment and resources, mobility and physical access. It was up to me to prove my fitness for the job and to provide any support I needed to overcome the barriers. I considered at the time my employers (the local education authority) and the university tutors to be extremely facilitative and understanding, accepting that I had to prove my worth and that it was not their role to remove the barriers for me. I was, however, sensitive to their attitudes and to the attitudes of prospective employers when I qualified as an educational psychologist in 1986. The 'big idea' of the social model of disability (Hasler, 1993) had been propounded (Union of Physically Impaired Against Segregation, UPIAS, 1976) and, whilst being the dominant UK understanding of disability amongst disabled activists and researchers, was not yet shaping social and governmental policies.

It was not until 2001 that an equalities adviser in the local authority, who was a fellow member of an advisory group, questioned me about my situation and pointed out that I was entitled to seek government and employer financial support in overcoming some of these barriers to do my job. Changes had come about as a result of the Disability Discrimination Act (1995), which had introduced new rights for employees and had repealed parts of the 1944 Disabled Persons (Employment) Act. It was now unlawful for my employer to treat a disabled person less favourably than anyone else for a reason connected to their disability unless there was good cause. The Employment Service now had advice, information and support services to support disabled people into employment. Because I was already employed, no one had specifically told me about this and after various applications I was able to seek adaptations to my working environment, financing for equipment and personal assistant support, which I had previously provided myself (Keegan, 1995).

As a tool for social justice, together with legislation, the social model has undoubtedly moved societal thinking and social policy forwards. However, there are other issues to be considered as well as the removal of physical and material barriers and other models, outlined in Section 1.3 above, raise the need to address attitudinal barriers and individual impairment. In particular the affirmative model (Swain and French, 2000) and the interactional model (Shakespeare, 2006) seem to have relevance for me in my personal and professional life. See Section 1.4 for a full review of these models.

As a psychologist, I am very conscious of my discipline's focus on the functional limitations of the individual (Lawthom and Goodley, 2005) and I support the need to take into account the interaction of factors and perspectives surrounding a 'predicament' (Shakespeare, 2006) to find the best ways forward to meet the needs of the children I work with. I became aware early on of medical versus social model thinking as it applied to perceptions of disability and I have always valued being seen as the person and professional I am first, with any difficulties presented by my impairments perceived as barriers which can be overcome through the application of creative thinking and anticipation.

I was, for about 10 years, the link EP working with the secondary resourced provision which the young people in this study attended, though at the time of the interviews I was no longer in this role, having moved to be a team manager in another area. Two of the children knew me in this latter role, because they had helped me to interview future EPs for my team. I had worked with one pupil briefly, two years previously in my link EP role

and some of the pupils had been in a group I had briefly interviewed, with an inspector colleague, as part of a strategic monitoring role of resourced provision that I have on behalf of the local authority. None of these contacts had been long term or sustained, but I was no doubt familiar as a visitor to the school to a number of the participants.

As an educational psychologist, I am accustomed to establishing a non-directive, counselling relationship with children and young people (Rogers, 1965) which influenced the way I interacted with the pupils in this study, where I drew on these skills to facilitate the interviewing process. I became increasingly aware of utilising these skills to facilitate the pupils' understanding and participation, to ensure that they felt heard and to seek further clarification of what they had said by reflecting back phrases they had used as the interview progressed.

2.4 Participants

A resourced secondary school in Hampshire was identified, which had up to 30 pupils with statements of special educational need for significant 'physical disability' registered at any one time in the resourced provision (see Appendix 1 for a description of the research context). The head teacher was approached and asked to give permission for the study to take place. This granted I met with the year 9 pupils as a group on two occasions (2004; 2007) to explain about the study, and to ask them if they wished to participate. Several pupils wanted to take part on each occasion and I gave out letters for them to give to their parents or carers, together with permission forms to return. Once these had been returned to me by the school I then arranged to interview each pupil separately at a time which was convenient to them and the school. On the second occasion, I also asked previous participants if they were happy to have second interviews and three agreed to do so. They were now year 11 pupils and were interviewed in January 2007, before their GCSE examinations (see 2.4.1 below).

The individual interviews in this study took place in December 2004 and between January and June 2007. Appendix 2 gives details about the participants and shows their ages at the time of their interviews. In the text pseudonyms have been used, to protect the pupils' anonymity. In order to protect the identities of the pupils who took part in this study, I have not described their impairments in the body of the thesis or named them in the summary given in Appendix 2. It is not unusual practice in qualitative research for researchers to change the names or characteristics of study participants in order to protect their identities and ensure anonymity (Wiles *et al.*, 2006). Although the participants "were individuals

who were probably not easily identifiable to people outside of their immediate group and for whom identification might result in embarrassment or annoyance rather than harm” (Wiles *et al.*, 2006) I did view confidentiality as important and I have tried to ensure that the views of individual participants cannot be easily identified. It can be viewed as undesirable to change the characteristics of individuals when presenting data in order to protect their identities, since this might compromise the integrity of the data (BSA guidelines, 2004:4, quoted in Wiles *et al.*, 2006), however the Social Research Association (SRA) guidelines view changing identities to protect anonymity as necessary, so long as researchers “carefully weigh up the potential damage to data resulting from changing details versus the potential damage to the participant of identification” (also quoted in Wiles *et al.*, 2006). I have certainly tried to do this in the present study, including being transparent about what changes I have made (see also section 3.5 below).

During 2004 – 2005 attempts were made to interview disabled pupils in mainstream schools without a resourced provision. Only one interview took place in April 2005 and this was eventually excluded from the analysis so that this study could solely focus on the pupils attending the resourced provision in one mainstream secondary school.

Therefore my analysis was based upon 14 transcripts, ten from pupils who were currently in year 9 and three second interviews with pupils in year 11, plus a third interview with one of the year 11 pupils, because a substantial part of the recording of his second interview was lost, and I only had a partial transcript of the second interview and my retrospective notes from which to work.

2.4.1 Second interviews

A number of the pupils had said they would be happy to talk again about a summary of their responses. I revisited three of the pupils I had interviewed when they were in year 9 again in their year 11 and presented to them short sections of the transcripts which I had identified as of interest and asked them for further comment. In this way I explored some of the interpretations I had tentatively placed on the language and phrases they had used and determined what degree of salience these issues had for the children themselves (Smith, 1994), thus promoting an ethical approach for potentially less powerful participants and also giving a perspective on these pupils’ self-reported experience at a different point in time. The insights gained from this process, as well as the ongoing iterative analysis, were then incorporated into future interviews with new pupils by asking for their reflections on the categories identified, if these had not already been mentioned by

them. Where multiple interviews have been used the data has been treated as an extension and expansion of the original interview for the purposes of data analysis (see Flowers, 2008, for a discussion of the use of multiple interviews with the same participant).

2.5 Analysis

The interviews were videotaped and this proved very useful since several of the young people had speech impairments which made it difficult to always hear what they were saying, in spite of repetitions, and in addition the importance of their body language and non-verbal communication was recognised (Watson *et al.*, 2000). It also allowed me to give my full attention to the young person and listen carefully to what they were saying. The video tapes were fully transcribed and every effort was made to record word for word all of the comments made by the young people and myself. Long pauses (over three seconds) were recorded, and emphasis and repetition were noted, together with relevant non-verbal behaviours such as laughter or smiling. (An example of an annotated transcript is given in Appendix 6).

2.5.1 Initial focusing

A number of qualitative researchers have indicated that the beginning of the analysis (which started after the first interview took place and continued throughout the interviewing process) has been a particularly difficult time for them as they feel very close to their data and cannot see the patterns and influences in them (Krieger, 1985; Hughes, 1994). They have found it useful to start off the process by writing accounts of their observations/conversations retrospectively and reflecting on their own emotions/feelings/thoughts before, during and after the sessions. Hughes describes ‘observational notes’ ‘theoretical notes’ and ‘methodological notes’ following the principles elaborated by Schatzman and Strauss (1993). I decided to try this approach with my analysis of the interview data from three year 9 pupils and their subsequent follow-up interviews in year 11.

I began by describing my overall impression of the course of the interviews (‘observational notes’), the themes which felt dominant, from the point of view of the pupil and which I felt were over-riding my attempts to ‘stick to’ the semi-structured interview schedule (‘theoretical notes’). I then began my analysis of the interview transcript using grounded theory. From this I was able to draw out categories which seemed dominant for that pupil. In the second interview I shared these categories with the pupil, asking for their reflections on the category and any current observations or comments. In this way I was able to

validate my early choice of categories with these pupils and then build on these, also exploring inconsistency and difference where specific concerns of a pupil appeared to contrast with more general concerns described by other pupils.

2.5.2 Coding for categories and themes

All of the interview transcripts were included in the analysis, in the process of coding the transcripts and following through the core categories to themes. A qualitative analysis of the data produced by the interview transcripts was undertaken. I read through each individual transcript several times, first identifying key issues, then using coding throughout the transcriptions to look at the pupils' perspectives. As with other qualitative approaches (Strauss and Corbin, 1994) the approach used here emphasised the inclusion of the perspective and voices of those being studied. In addition my distinctive position and interpretative role as the researcher was recognised. The approach I used emphasised developing theory through reference to the data itself. Thus the hypotheses generated by my interpretation of the data were verified throughout the research project through reference to the data. In this way, Strauss and Corbin (1994) describe how a conceptual density can be evolved:

“‘Conceptual density’ refers to richness of concept development and relationships – which rest on great familiarity with associated data and are checked out systematically with those data’ (Strauss and Corbin, 1994, p. 274)

This approach was characterised by constant making of comparisons, concept-related questioning of the data, theoretical sampling driven by theoretical sensitivity and systematic coding procedures.

Using grounded theory allowed for an iterative process of data collection and analysis which involved reflecting upon the data as it was collected to develop categories grounded in the data, and then checking these out with participants in subsequent interviews rather than trying to impose some pre-defined categories upon the data, which may not have coincided with the pupils' perceptions of important issues. However, the interview was semi-structured with a series of open-ended questions covering a wide area of academic and social experiences at school, with several prompts to follow these up. If the pupil introduced or pursued a topic outside these guide questions this was followed with them until they finished; the questions would then facilitate continuing discussion. Thus there

were inevitably topics introduced by the interviewer as a starting point to eliciting the pupil's views with the perspectives on these taken from the pupils' responses and other issues raised by the pupils themselves. (See Appendix 3 for the questions/prompts used).

Tesch (1990) discusses the use of coding to decontextualise and recontextualise the data allowing the researcher to think about and with the data, to identify those issues of importance and relevance to the pupils themselves. The interactive processes used in grounded theorising (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Glaser, 1998) are also involved in other kinds of ethnographic research and Coffey and Atkinson (1996) describe such approaches to categorising and conceptualising qualitative data. These approaches depend on coding the data and using the codes to retrieve significant segments of data for further analysis. This allows for a thematic analysis in accordance with an emerging conceptual scheme (Boyatzis, 1998). This approach was applied to the data collected in the interviews. The transcripts were read through several times and analysed to determine categories of data having some common element or theme. Codes were used to link the data fragments to the emerging concept and to aid the organisation and retrieval of the data as the interpretative process progressed. The codes were also used to help reflect on the data.

As the coding progressed and categories came to mind, these were recorded on a computer file. The objective was to continue this process until one or more category started to emerge with a high frequency of salience for one or more of the young people, and to be connected to a number of the categories which were emerging (Dick, 2005). This core category was then followed through, ignoring sentences which did not relate to it, and coding was for the core category, other connected categories, and properties of both. Identified connections were recorded in the file until 'saturation' was achieved, at which point I ceased coding for that category and returned to other core categories which had emerged to repeat the process again. Axial coding then took place, where each category was refined, developed and put in relationship with the other categories, creating themes. (Figure 4.1, p. 73, illustrates the key themes which emerged, and their constituent categories).

2.6 Presenting the interviews

When writing up my results (Chapter 4) I have taken several editorial decisions. Having transcribed the tapes in some detail, word for word, I have then edited the quotations in the text, by removing multiple repetitions and many of my verbal affirmations, delivered at the

time to keep the conversation with the pupil going, i.e. 'Right', 'OK', 'Yeah', 'Mmm', since these are not necessary for the reader of my thesis, though it was important to transcribe all of this for my analysis. Where they were felt to have added something to the interview process by way of seeking further clarification or asking new questions, they have been included. This is not to deny that these facilitative comments were not significant to maintain rapport and put the young person at ease, and feeling listened to, however, they are not important to the overall description of the issues which were significant to the pupils. There was also more editing for some pupils who were hesitant and repetitive, because of their lack of clarity, or because of their slow output of speech, in that they used repetition in their speech to aid their processing.

Chapter 3: ETHICAL ISSUES

3.1 Introduction

In order to address the first research question, which focuses on the need to promote the engagement of the participants and to ensure that their views were heard, a number of ethical issues were considered in the formulation and conduct of this study, following a set of guidelines proposed by Lewis and Porter (2004), to be considered when interviewing children and young people with learning difficulties. By learning difficulties they are referring to pupils with severe or profound learning difficulties, where verbal communication is limited. However, these guidelines can be applied to the present study, where a number of the disabled youngsters had associated learning difficulties, although verbal communication was appropriate as the method of interviewing used. The guidelines were formulated and developed through a series of ESRC-funded workshops on 'Methodological issues in interviewing children and young people with learning difficulties' (2001–3) held at the University of Birmingham and attended by professionals from Education, Psychology, Health, Legal and Social Services. These guidelines fall into 10 broad sections: research aims, ethics (encompassing access/gatekeepers; consent/assent; confidentiality/anonymity/secrecy; recognition, feedback and ownership and social responsibility), sampling, design, communication and methods. I will discuss how consideration of these shaped the present study.

3.2 Research aims

The guidelines propose that research aimed at eliciting children's views, particularly those with learning difficulties, should aim to be both inclusive and participatory in nature, useful to its participants, bring about change and cause no harm to the participants (Lewis and Porter, 2004, p. 192).

The present study was carried out with the pupils' full informed involvement. Those participating were able to contribute their views and were clear about the aims and purpose of the research. Care was taken to ensure that the participants were not harmed in any way by being involved in the research, through respecting their confidentiality, negotiating the interview timetable with them, checking out my interpretations of what they had said with three participants. The research aimed to raise awareness of policy makers and practitioners of the experiences of these pupils in the hope that future development of provision will take these children's perspectives and experience into account and the pupils were fully informed of this aim.

3.3 Gaining access

The guidelines raise the issue of frequently needing the permission of a third party to be able to access the participants: “They will have their own views about the value of research and who should, or could, contribute to it” (Lewis and Porter, 2004, p. 192). Throughout this research, in order to gain access to the pupils in schools it was necessary to involve a third party, primarily the special educational needs co-ordinator (SENCo) of the school and then, indirectly, the head teacher and parents. (In 2004 I also consulted with the specialist teacher advisers to the non-resourced mainstream schools to find out more about those pupils, though ultimately, these were not included in the study). I was able to identify the young people I wanted to contact through independent criteria – that of their having a statement of special educational needs for ‘physical disability’ and attending mainstream schools with (and without) resourced provision. These pupils have ‘low incidence disabilities’ (DFEE, 1997).

“These are pupils that the Government recognised in its vision of *Excellence for all Children* as having the most ‘severe and complex difficulties’ and as continuing ‘to need specialist support’”
(DFEE, 1997, p. 53).

The ‘gatekeepers’, (particularly the direct contact adults in the schools), had some impact on shaping my access to the pupils. They had their own views about the value of the research and their own relationship and history with the pupils involved. For instance, in one situation involving a pupil attending a non-resourced secondary school, when I initially discussed the research with a Special Educational Needs Co-ordinator (SENCo) and talked about the pupil I wanted to see, the SENCo informed me that the pupil was not speaking to her at the moment, because the SENCo was insisting that the pupil could not use the upper classrooms in the school until some equipment had arrived to carry the pupil in her wheelchair up the stairs (for health and safety reasons). The SENCo did agree to speak to the pupil, to ask if she would see me. I then heard nothing for a number of weeks. On enquiry, the SENCo was away from the school, on sick leave. Later, I was able to make contact, to discover that the pupil had still not been asked, but the SENCo considered the time was now right to do so, particularly as the pupil was now being allowed to walk upstairs and access her lessons there. The pupil immediately agreed to see me and the interview was able to take place, though over a term later than I had initially planned. Locating and gaining access to the sample through third party gatekeepers is a significant issue and one which may require great sensitivity and persistence on the part of the

researcher (Morris, 1998). Ultimately, in this study, it proved too difficult to find an adequate sample by following this procedure across a number of non-resourced secondary schools and the research focused instead upon a sample of pupils in the same resourced secondary provision. In this school I was able to meet with all year 9 pupils on two occasions and explain the research aims to them, so that they could make their own decision about whether to be involved.

In addition to the need to access the pupils through a third party, there was a further issue regarding my position as an employee of the local authority. As a high status professional working for the local authority I was able to claim the privileges of this role when negotiating the backing of the LA and permission from the head teachers and governing bodies of the schools. This always had implications for the management of confidential information I received from pupils and for ensuring anonymity for both pupils and school in the findings shared within the local authority. This may have also influenced parents in their decisions to agree or refuse to their child's involvement.

3.4 Informed Consent

The importance of informed consent is raised in the guidelines and was of particular concern in the present study. I tried to ensure that the pupils understood what the research involved and that they could refuse to participate or could withdraw at any time. I was keen to avoid 'tokenism' and to ensure that the participants agreement to take part in the research was based on real choice, that they understood that their participation was voluntary and that they were offered the right to refuse for whatever reason (which did not have to be stated) if they wished to do so. Lewis and Porter (2004) point out that the actions of the gatekeepers can be mistaken for consent on the part of the sample, and that, even where proxies are used, it is still important to provide opportunities for ongoing assent or dissent from involvement. In this way the consent process should be seen as ongoing and the participants should be reminded, at appropriate intervals, of their right to withdraw from the research at any time. I spoke to the pupils about the research and they made their own decision to become involved, though they were required to get their parent or carer's signature for this to take place.

3.5 Confidentiality and anonymity

A further guideline is the importance of ensuring anonymity, particularly with "minority populations, which are heterogeneous in their characteristics" (Lewis and Porter, 2004, p. 193). This was always a key issue in the present study, which I recognised might be

particularly difficult because of the small numbers involved, and the fact that there are only four resourced mainstream secondary schools, (of contrasting size) in the county. I realised that this might make it relatively easy to identify participants. Throughout the work it was important to maintain confidentiality and participants were promised anonymity so care was taken to ensure that what pupils said was not used in a way which might enable them to be identified. Only the type of provision has been identified, rather than the actual school or pupils.

All of the pupils I interviewed, except one, were boys and, in order to maintain anonymity for the female pupil I gave her a male pseudonym and used the male pronoun when necessary. There were two occasions where she mentioned issues which would have identified her sex, one related to sexual harassment and one to a comment by an occupational therapist about being 'ladylike' and, because I felt these were important to include as part of the pupil voice, I have masculinised the issues so that she cannot be identified. Because of my small sample it would not have been possible to consider gender differences and so I feel this was justified, and important, so that this pupil's voice could be heard.

The population I have worked with (pupils with physical impairments and associated learning impairments) are particularly vulnerable to abuse (see Morris, 1998) and this increased the possibility that disclosure might occur during the interviews. I recognised that this might impinge on my promise of confidentiality to the participant, and so at all beginnings of listening to and talking with pupils, I stated clearly that I had a duty of care to the pupils, which required me to pass on specific information if I felt they were in danger. I never had the need to do this.

It was possible that another form of disclosure might occur if the pupils I interviewed raised my awareness of schools not complying with the requirements of government legislation, e.g. the SEN and Disability Act, 2001, and issues such as the poor use of support staff and resources to the detriment of the pupil. I considered my response to such situations and concluded that, if there were situations where great concern was generated, given my role as an employee of the county council and a responsible professional, I would have a duty of care to mention such concerns to other visiting professionals with whom I had contact, who might follow up the issues indirectly with the schools, through making general enquiries and without revealing the source of their initial information. This was already current practice between visiting support professionals in Hampshire. However I

continued to be aware that I needed to protect the anonymity of the pupils I was interviewing as I had agreed this with them and so any such disclosures would have to be treated very sensitively and with great care. A balance needed to be struck between these competing responsibilities and I accepted that at times I would be unable to take action on the pupil's behalf, but could only encourage them to report this themselves at the end of the interview. If more direct action was indicated, for example, if I felt the pupil was at risk, then I would refer once more to the requirement for me to pass on specific information and would discuss this with the pupil during the interview. In the event such situations did not arise. However, I found at times that some of the issues raised by the youngsters were quite significant and personal in their lives and they appeared to need help to work them through. I was very tempted to follow these up in my professional capacity of educational psychologist for the local authority, but I felt unable to pursue the issues from the perspective of the researcher because of the explicit, agreed boundaries set by the research relationship with all parties (including pupil, parents and school and, in fact, the link educational psychologist for the school). This perhaps indicates the need for a different type of research in which it is possible to be both researcher and supporting professional (action research). I was always aware of my 'duty of care' and in the present study I decided that I would ask the pupil for their 'permission' to mention my concern or their issue to their teacher or parent or the link educational psychologist for the school as appropriate if necessary, in addition to stressing to pupils at the beginning of the interview that I would have to inform the appropriate person in the school if I thought they were at risk of harm. I did this on one occasion.

3.6 Ownership

Lewis and Porter (2004) raise the issue of who 'owns' the data produced in such participatory research, pointing out that it is generally presumed to belong to the researcher. They suggest "as a minimum, participants should have the opportunity to receive feedback from researchers about the outcomes of the study" (p. 193). I considered carefully the question of 'ownership' of the views and experiences gathered. This research was ultimately planned and initiated by the researcher and as such the researcher holds the data and draws conclusions from it. It is generally assumed that the data belongs to the researcher, with some authors proposing that the researcher acts as a banker, retaining the data, but giving others access to it (Kellett and Nind, 2001). Lewis and Porter (2004) comment that in an inclusive context, this might suggest that schools should have access to such information, which would have implications for confidentiality. In the present study, the data was felt to be 'owned' jointly by the researcher and the participant who had

supplied that particular interview and feedback, with an agreement that the tapes would be wiped clean when the research was completed. I shared with some participants a summary of the themes drawn from their first interview verbally during a second interview and asked them to comment on my interpretation of what they had said. These pupils' comments and reflections were then included in the analysis and so are incorporated into my reporting and interpretation of the findings though, at the end of the day they are my interpretations (see Chapter 4 Findings and Interpretation). At the end of the study, the findings will be disseminated to those who have taken part in an accessible format through the school (Goodley and Moore, 2000).

3.7 Social responsibility

It was also important to be aware of the complexities of being an adult, trying to learn from children. In her work on gender differences in American middle schools, Barrie Thorne comments that “when adults research children they ‘study down’, seeking an understanding across lines of difference and inequality” (Thorne, 2004, p. 254). The adult researcher's social responsibility towards the children they are studying will require them to be sensitive to this power inequality in their work with children. There can be an apparent sense of familiarity when studying “those who are defined as learners of one's own culture” (Thorne, 2004, p. 254). To learn from children it is important that adults suspend the assumptions they have, that they know what children are like and instead view the familiar as strange. In addition, adults inevitably have privileges in schools as adult visitors, and in my case, a high status visiting professional. I was aware of the potential impact of this on the research situation, and particularly the power relationship between myself and the pupils with whom I worked (Robinson and Kellett, 2004; David, *et al.*, 2001). In addition, as mentioned previously, there were also issues regarding potential moral dilemmas relating to the uncovering of uncomfortable information relating to the practices or ethos of the school I worked in and I was aware of my duty as a researcher to report the data I uncovered, whilst maintaining relationships with others, my employers, school staff and participants (Lewis and Porter, 2004).

3.8 Conclusion

Answering the first research question addressed in the present study required an explicit consideration of the ethical issues in the methods used in relation to ensuring that the research was not experienced by these disabled pupils as something imposed upon them for the benefit of the researcher:

“Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as a failing to improve their material circumstances and quality of life” (Oliver, 1992, p. 105).

Oliver (1992) suggests that traditional research experiences are often oppressive and alienating to many of the research ‘subjects’. Following the ethical guidelines produced by Lewis and Porter (2004), in the context of seeking the views of disabled children with learning impairments, this research explicitly addressed these issues in the context of the present study to promote the engagement of the participants and ensure their views were heard.

4.1 Introduction

What did these disabled pupils, attending a resourced secondary mainstream provision, describe as their experience of school? The process of analysis described in Chapter 2 led to the identification of the following key themes encompassing a number of categories which have been illustrated in the diagram below (see Figure 4.1). Each is now discussed in turn.

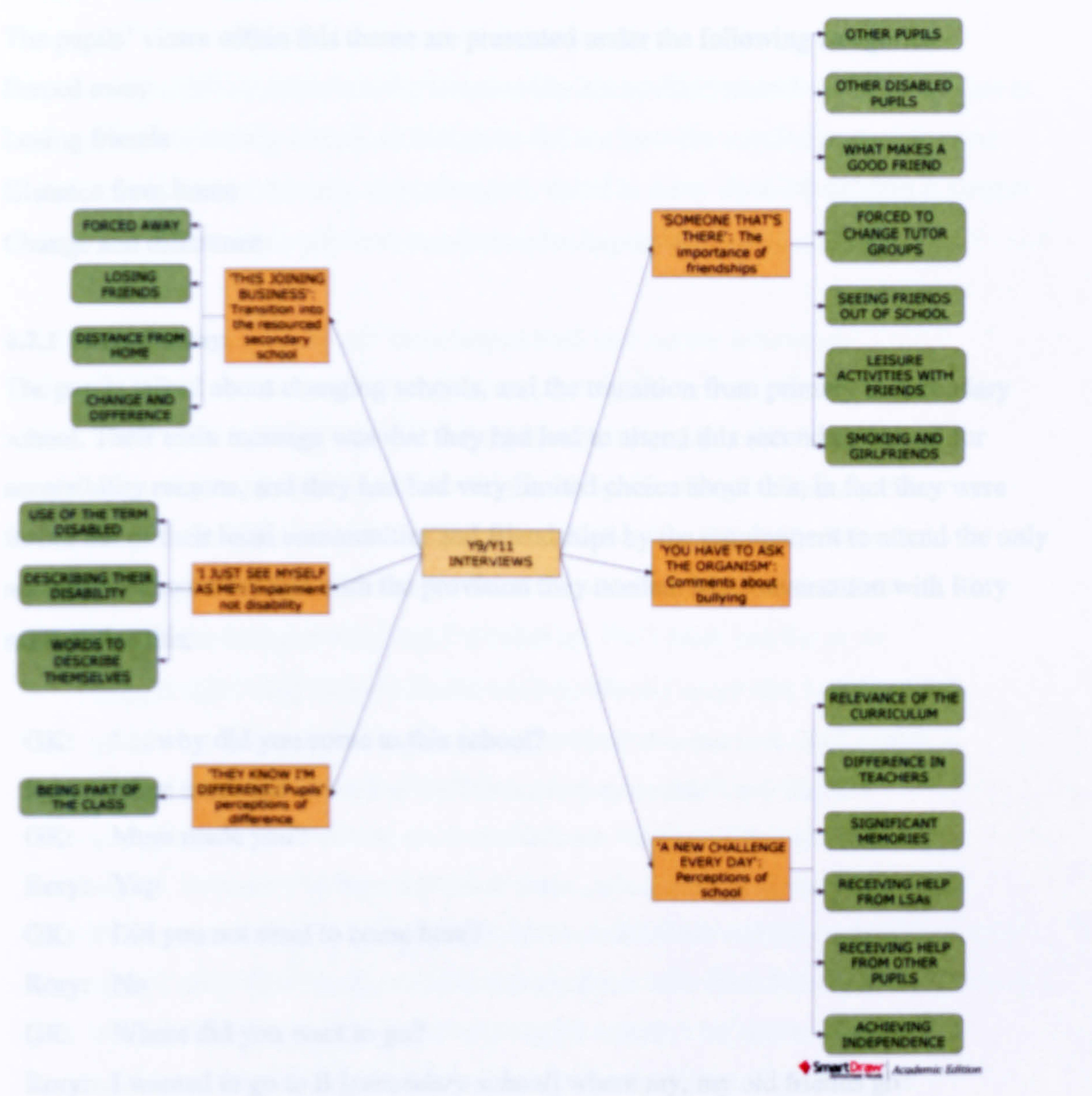


Figure 4.1: Key Themes and core categories identified

4.2 ‘THIS JOINING BUSINESS’: Transition into the resourced secondary school

All the pupils had something to say about their transition into the resourced secondary school. Most had come from mainstream primary schools. One pupil had been permanently excluded from his primary school because of his behaviour, so had been at home, receiving home tuition for over 6 months before he began at the secondary school. Two pupils were from a primary special school which was for pupils with ‘moderate learning difficulties’, but also had 10 places for children whose primary need was seen to be ‘physical disability’.

The pupils’ views within this theme are presented under the following categories:

Forced away

Losing friends

Distance from home

Change and difference

4.2.1 Forced away

The pupils talked about changing schools, and the transition from primary to secondary school. Their main message was that they had had to attend this secondary school for accessibility reasons, and they had had very limited choice about this, in fact they were forced out of their local communities and friendships by the requirement to attend the only accessible school available with the provision they needed. My conversation with Rory exemplifies this:

GK: ‘....why did you come to this school?’

Rory: Mum made me

GK: Mum made you?

Rory: Yep

GK: Did you not want to come here?

Rory: No

GK: Where did you want to go?

Rory: I wanted to go to B [*secondary school*] where my, my old friends go
but...

GK: And why couldn’t you do that?

Rory: [*Shrugs*] Mum made me come here because Joe was here

GK: Right your brother, does Joe have a disability too?

Rory: Yeah, he’s got the same thing, problem as me

GK: Right, OK so why couldn't you go to B?

Rory: Mum made me

GK: Can you think of any other reasons?

Rory: Because er this school's got the erm, thingy, physiotherapy ... And disabled er thingy thingy, I can't remember exactly

GK: Access

Rory: Yeah that's it

GK: With a lift and everything

Rory: Yeah. And, that's all'

Rory found it difficult to explain the reasons why his mother insisted on his attendance at the resourced secondary school, as though he did not have the vocabulary to talk about disability and its requirements, a characteristic noted in many disabled children (Connors and Stalker, 2007). Other pupils were much more loquacious and expressive.

When asked if extra visits would have helped Neil told me the following:

Neil: 'I had quite a lot but it was like um I think just because I didn't want to come they were kind of just showing me it again and again thinking I'd like it more if I saw it. But I didn't like it in the first place and showing me it again didn't help. But you know I've come up quite a lot, I knew what I was doing or whatever, I'd come up. But I think just the main thing is that I didn't have a choice so I was always angry that I couldn't go where my friends were going because I had to come here. And I think they're a bit mad about it as well because they couldn't see why I couldn't go to their school and I couldn't see why I couldn't go to their school. Because I've been to look at them...when wanted to move here, I've been to look at C [*secondary school*]. And I think that they weren't really... they didn't really want somebody there with disabilities and I wouldn't be able to get around very well, I wouldn't be able to go upstairs or anything. But I still would have kind of liked to go there if I could. But a lot of the schools just weren't adapted. And they didn't want to adapt either, it's not like we... it's not like they could do it and then you go.'

Neil did have the vocabulary to express his and his friends' feelings about the

situation of having to attend a school at the convenience of the system, rather than Neil having the same right of choice as every other pupil to move to the local secondary school with his peer group.

4.2.2 Losing friends

Having no friends on transfer was an issue for the pupils too.

GK: '....What about your friends, did you come here with any friends?

Sam: No just me.

GK: What was that like?

Sam: Because I knew no one, it wasn't very nice, but I've made loads of friends now.'

Transferring with one other disabled child created its own problems of dependency for one pupil:

GK: 'So when you came to this school did you know anybody when you arrived?

Neil: No, well I knew another boy who's in a wheelchair. He used to be at my school but that's it

GK: OK and how's it been making friends here?

Neil: Um hard work a lot because the boy who I moved up with I'm kind of like really close mates with him and he kind of doesn't talk to anybody else or anything, he kind of relies on me a lot. So I kind of don't see my friends a lot because I'm always with him. Because he kind of needs me to do stuff or whatever so I don't see them a lot...'

For Neil, making new friends at the resourced secondary school had been inhibited by a sense of loyalty to the needs of a fellow disabled pupil, who came from the same primary school and had not made new friends so was dependent on having Neil around.

However, for Fraser, meeting and getting to know new people was something he felt had been good about his transition to the resourced secondary school. As such, he had a positive attitude to the school, even though he had found it difficult at first.

One pupil mentioned the fact that there are two rival football teams in the neighbouring cities, and this had been an issue for him, since most of the children in the school supported the opposing team to his. In his view, this affected whether other pupils would help him, and may have been a factor in the bullying he frequently referred to. This was another example of the impact on some of the pupils of having to attend a school out of their own neighbourhood.

4.2.3 Distance from home

Another major issue of concern to the pupils was the increased distance from home to school, by attending the resourced provision:

Sam: 'I didn't like it when I first came because I live in F and have to come all the way here every day.'

Other pupils mentioned the impact on friendships, as they were unable to see their school friends out of school because of the distance. In addition the need to use specially arranged transport that left the school promptly resulted in Neil not attending his tutor group at the end of the day and missing notices for extra-curricular activities, and he reported that there was nothing in place to rectify this. For another pupil having to get up earlier to go to the resourced secondary school than he had done to travel to the local primary school was a significant issue which affected him all day, in terms of tiredness.

4.2.4 Change and difference

Change and difference was a major issue for a number of the disabled pupils as it often is for any other pupils transitioning to the secondary school setting (McGee *et al.*, 2004; Evangelou *et al.*, 2008), but compounded for these pupils because of the factors mentioned above, i.e. not transferring with friends; distance from home, etc. These differences included the size of the school, the timetable and moving to different teachers and the behaviour policy and rules:

Sam: '[4 second pause] Probably it was just that I was worried coming to this school.

GK: Why were you worried?

Sam: Because a different school...And everything's different....to me.

GK: How's it different?

Sam: It's much bigger, very easy to get around.

GK: Erm hum, anything else?

Sam: No. [9 second pause] The timetable I think. Getting used to the timetable.'

Aidan found rules and sanctions difficult at first:

Aidan: 'Put it this way, I had a big shock when I come here, because the way they dealt with stuff there is a lot different from the way they do it here, so before when I got expelled, the first few weeks until I actually got used to it, but now I'm alright.'

GK: 'So you were actually excluded when you first came here. Why do you think that happened?

Aidan: Just because I'm...just because I was getting used to it. And I'd just come back from loads of exclusions, so I'm like, because like, next time it's going to be permanent so I'm trying to not be, not be totally different, but try, trying to be how I was when I first started school. I'm still having moments but like....I don't think people know when I'm going to, like turn. I don't think they realise that if they just leave me alone, teachers as well, I will just eventually, just be back to normal, if you know what I mean.'

For some pupils, this difficulty of coping with change and adapting to new settings was still around in year 11 and they still recalled the difficulty of it. In his second interview in year 11 Ben talked about moving onto college, and sticking with a college he knew (because of doing a course there whilst in year 10 at school) so that he did not have to learn his way around again.

Ben: 'That's why I chose to go to F College because I know that college better than any of the other ones. I know its layout...I know where everything is. And said I'd prefer to go to somewhere where I knew. Yeah, instead of... instead of you know being put in the lion thing, you know what I mean?

GK: Yeah, yeah.

Ben: Just in a totally new place and I said it was different enough learning where everything is here. So I said if I went to a new college, if I went

to a different college to one I've already been, it would be like repeating that all over again.'

Ben was keen to emphasise that he would go to another college nearer to his home if he had to, even if it was strange, perhaps wanting to stress his resourcefulness and maturity, or perhaps indicating that he might have chosen the college closer to his home, if given a choice initially, rather than already having been to the more distant college because of the arrangements by the school.

Later in his second interview Ben talked about settling into a new school:

Ben: 'Yesterday I said to um... who was it?... I said to him... who was it I said it to?... I said... I said it to you last week, said it takes a bit... it's going to take a bit of time but eventually it will happen. It's not going to happen straight away but do you understand what I mean?

GK: Yes, I remember that, yes. Yes, so what came across to me last week is that year 7 can be quite a difficult year for people.

Ben: Yeah because I can understand what you mean because I felt the same way. When I was in year... when I was in this joining business, because it's done in year 7, do you know what I mean?

GK: Yes.

Ben: So um yeah because it's a new experience, isn't it?

GK: Yes.

Ben: Moving onto new things and it's a lot to take in.

GK: Erm hum, yeah and then you felt and some of the older students felt that it got better as you go further up the school.

Ben: Yeah it was um... not that it got better, it got better but it's not the word I'd use. It's... it was better, not worse but that's not the word I'd use. The word I would use, it becomes more easy, you know. More aware.'

Note Ben's use of the term 'this joining business' and the difficulties he experienced in year 7 and still remembered in year 11, empathising with the younger pupils. Ben was not happy to accept the vocabulary I used and insisted on expressing the change over time in his own terms to get his point across – that the pupil comes to have more awareness in the new setting, given time.

These issues, presented by the pupils themselves, raise significant factors for consideration by policy makers and practitioners in planning secondary provision for these youngsters with physical and learning needs. They clearly wish to have a real choice when choosing a school and do not want to be barred from schools in their locality or from going where their friends will be going because of access issues or the attitudes of the schools (social model issues). Having made a real choice, they then would value getting to know the environment and layout, the rules and expectations, the timetable, and some of the other pupils before they transfer. Having made the transition, it is important to continue to talk with the pupils and listen to their experiences to help iron out any difficulties, e.g. Neil's ongoing misplaced guilt in feeling that he has a duty to support his disabled peer from primary school, at considerable cost to his own social experience and potential happiness; ensuring school transport issues do not interfere with the pupil's access to tutor time and important information.

4.3 'I JUST SEE MYSELF AS ME': Impairment not disability

During my conversations with the pupils I had chosen to use the terms 'disabled' and 'disability' to set the framework for the research and to initiate the individual interviews, without knowing what understandings and emotions the pupils attached to this terminology. As the interviews progressed I began to check out with the pupils more what they felt about the term 'disabled' and whether it was a descriptor they would use themselves (Priestley *et al.*, 1999; Watson, 2002). In reading through the transcripts I also became aware of how the pupils talked about aspects of their identity when unprompted by me, during their descriptions of their experience at school and in their community (Gwernan-Jones, 2008). These conversations revealed how the children identified themselves in relation to disability and how they perceived others as identifying them.

Most of the children said they would not use the term disabled themselves, though they tolerated and accepted its use by others, including me. When I asked them to describe their disability they actually talked about their impairments and the limitations created by these, often denying that they were very significant.

4.3.1 Use of the term 'disabled'

David identified himself with my definition of 'pupils who are disabled' by pointing to himself when I introduced the term.

However, at another point he seemed unsure the word 'disabled' applied to him:

GK: '.... how did you feel about the word disability when I used that, are you happy with it?

David: I don't mind that at all

GK: Is that a word you might use yourself?

David: A lot of our people use it and I don't mind it

GK: Yeah and does your Mum use that sometimes?

David: Yes, she does when me and her are talking about things that we've seen on television

GK: Mmhm, and would you think that applies to you?

David: Well I'm not sure actually but I don't mind people using that word'

Rory did not think it was a word he would use, because he did not want to, though he recognised that other people used it. Fraser said he 'sometimes' used the word, but when I ask him what it meant he seemed unable to say:

Fraser: '[6 second pause] I don't know sort of like some other people they say... you know somebody who's disabled they just instantly think that um [3 second pause] that they can't do anything and they're like useless, but it doesn't actually mean that.

GK: OK so what do you think it means then?

Fraser: [8 second pause]

GK: Sometimes I use the term physical difficulties because that's what it is, isn't it really for us, yeah?

Fraser: Yeah, yeah, like, I don't know like um, I don't know it depends on what disability a person's got.

GK: Yeah.

Fraser: It's what, out of my hands...'

This suggests that Fraser could not put into words what he wanted to say about disability, though he clearly had some considerations going on and attached negative interpretations to it. Disabled young people like Rory and Fraser often lack a positive language with which to discuss difference and disability and tend to minimise or deny their differences and are often not encouraged to talk about their disability at home or at school (Connors and Stalker, 2007).

When I discussed with Rory whether he saw himself as a disabled pupil he was difficult to engage, and similarly to Fraser seemed to have a lack of language to talk about it. Later he suggested a positive view, but was unable to specify why.

Aidan, in his second interview, when asked if he remembered what the first interview was about commented:

Aidan: 'Something to do with school and me being disabled I seem to remember apart from that, I can't remember any of it'

Later in the second interview, I asked Aidan if he used the term 'disabled' himself:

Aidan: 'I don't think of it anyway. I see me as me, that's what I'm used to so'

He then went on to say he did not see himself as disabled, because he had always been as he was now – not an acquired impairment, which results in a change of life style. This has been noted by other researchers (e.g. Rousso, 1984).

Aidan: 'My case's different so, be a bit different if I weren't the way I am, if I'd fallen out of a tree or car crash or, like, I don't know, I've injured myself playing sports or like, Superman, he fell off a horse and he was put in a wheelchair for that, it's slightly different how I interpret me 'cause I've been born like it, that's what I'm used to, I just see it as normal...so, it's not that, I won't get like all, what's the word, depressed or, what's the word, cause that's what I'm used to, whereas people that have, for example have been paralysed or fell off a horse or anything would interpret it differently because, obviously, the change in life style, so, yeah'

It would appear that Aidan required a life changing experience to prompt a reflective contrast to define having a disability; without this he seemed to have no reflective vocabulary or concepts to describe his views. I go on to ask Aidan how he felt when I use the term:

GK: '..... So, how do you feel then when I use the term 'disabled person'?

Aidan: I don't care, as I said, that's what I'm used to, so...

GK: So that's a term people use, that's used in school and...

Aidan: Yeah, like people, when I argue with em they goes go, get some new legs or spac or retard, I don't care 'cause it's like, because that's what I've, because when I argue with people that's all they can come up with so it's not like it's anything new so it doesn't bother me, whereas yeah, people can have a go at me until the sky turns purple and I don't care because I'm used to it.'

Aidan accepted the use of the term from other people, but he then equated it with other negative terms that were used towards him, because of his impairment – saying he did not care, he was 'used to it', it was a part of him that he accepted.

Paul agreed that he saw himself as a 'disabled pupil' and felt other pupils became jealous of this:

Paul: 'I don't mind that because the disabled get a lot more help, which... and also the reason why they do it I think is that they're jealous because Paul has got a help.'

Later he reaffirmed that he was comfortable with the term 'disabled', but did not want to be treated differently because of this, contradicting his previous positive perspective on receiving 'different' treatment in the form of help:

GK: '.....And you were happy with the word 'disability'?

Paul: Yeah.

GK: And it's a word you would use.

Paul: Yeah..... The way I find it you're all individual, no matter what your condition is, you shouldn't be treated any different. I feel like I'm being treated differently.'

This perhaps related to 'being treated differently' in negative ways.

In the following example the young person described how he used negative terms to describe himself, when he was feeling down or fed up, since this was how he sees his impairment being perceived by others – clearly a negative perception.

GK: 'OK, so thinking about um the experience of being a disabled pupil. Are you happy for me to use that term disabled?

Neil: Yeah.

GK: Yeah because I mean that's the word that I as an adult will come along with but it might not be a word that you would use.

Neil: I don't really mind what people call me to be honest.

GK: Yeah, would you use that word yourself?

Neil: Um [*3 second pause*], it depends who I'm with I suppose. What we're doing sometimes you know, I don't think... we think differently I suppose ...But it depends on the day....

GK: Yeah, so tell me a bit more about that.

Neil: Um well normally I call myself disabled with sort of grown up people but then sometimes if you're having a bad day you say spastic or handicapped or whatever other people think of you, sometimes, I call myself that.

GK: Do you?

Neil: Yeah, it depends [*laughs*] what mood I'm in and what I'm doing.

GK: Why might you do that do you think?

Neil: Because you sometimes think that you know it's... like disabled is more politically correct or whatever you want to call it.

GK: Right, politically correct...

Neil: Yeah [*laughs*] yeah. And sometimes other people think oh, if other people call you spastic sometimes I don't see the point in hiding it from other people so you just call it spastic.

GK: Yeah, yeah. How would that make you feel though?

Neil: I don't do it a lot it's just on the odd day or whatever when I'm feeling a bit fed up, whatever'

GK: 'When you said near the beginning that sometimes you use less politically correct terms, um, was that because you feel angry and frustrated at times or why would you... you said it was to do with your mood?

Neil: Yeah, it's only like once in a blue moon but sometimes, I don't know, I just get frustrated with it sometimes, I think the fact that people always judge you before you've even done anything, said anything. I think sometimes it's getting annoyed and I'll just call yourself

something but I know it's not true or not right or whatever, and that's only once, you know... you know, if I get down, really, really kind of down....not very often

GK: Right, so when you say you call yourself that would that be in front of those people or...?

Neil: Um I think I only do it like... I don't do it in front of kids, you know, I don't want them growing up thinking, you know, like calling other people what I call myself, only now and again, but.... um sometimes I go to the cinema and you know sometimes you go to ask for a child or whatever and then everybody stares at you so I go, OK, I'm a spastic whatever you want to call it. But that's only every now and again I do that.

GK: Yeah, yeah really that sounds to me like you're getting really angry with them for staring, yeah.

Neil: *[Laughs]* Yeah. Well you know, it's normally more than just one thing, it's been like three or four things in a day that's happened to kind of...

GK: Built up.

Neil: Yeah.'

So Neil saw 'disabled' as the politically correct term, whilst acknowledging more derisive, negative terms which he might resort to himself, 'when really kind of down' – berating himself with a language he had learnt and which Aidan said he had 'got used to'.

Paul also reflected on the attitudes shown by other pupils, in this case about how he used the toilet, and got quite angry about this, clearly identifying with other disabled people, but not prepared to tolerate what he saw as inappropriate questioning from what he at first called 'normal' and then changed to 'able bodied people'.

Paul: 'I mean if another disabled asked me, sure I'd be fine with it because they know I have difficulties going to the toilet, all disabled people do, they need people to help them go to the loo, but normal people... oh I used that word again...able bodied students come up... when they come up to me and go 'how do you go to the toilet?', it's like, uh *[groans]*.'

Paul used the terms 'normal' and 'able bodied' and referred to himself as 'disabled' more than the other pupils in the study and this demonstrated his 'shared identity' (Shakespeare,

2006) with the disabled pupils.

A shared identity has certainly played a crucial role in the development of the Disabled People's Movement and the political campaigning for civil rights for disabled people, though as Shakespeare (2006) indicates, only a very small proportion of Britain's 10 million disabled people have been involved with this. The other pupils in this study seemed more reluctant to admit to seeing 'disability' as part of their identity (Watson, 2002). They frequently equated this term with negative connotations, particularly in the perceptions of others who are not disabled. Some references were made to the experience of disabling environments and attitudes of others outside of school, though this was seen to be variable, and gradually improving. As Neil says 'I think most of the time they're alright from what I can see anyway.... a lot better than what apparently they used to be, I wasn't around...'. Fraser notes that it may depend on who it is, i.e. people vary in their willingness to help, though he comments, 'most people want to help disabled people'. Those who are not helpful, 'I don't want anything to do with them'. He goes on to describe how he attends a social group for disabled children where he sees some volunteers being 'the first people to say....oh put my name down to help'. The bad experiences he has had relate to 'the people....the way some people react to you, treat you like you can't do much'.

These comments reflect the narrative of dependency on non-disabled people noted by Davis and Watson (2001), as discussed in section 1.13.1.

Aidan (in year 11) talked at length about his frustrations with environmental barriers such as a lack of ramps, limited aisle space in shops, as well as people who do not take his needs into account, even when these have been provided for, e.g. using disabled spaces on the buses.

He also talked about variability between other people's attitudes. He described situations in shops when female customers had expected him to move round the stand the other way, rather than moving themselves, even though he had to try to manoeuvre his large powered wheelchair. On one occasion another customer spoke out for him and Aidan noted the polarity of this situation, 'some woman started sticking up for me so it's a bit of both,the complete opposite of each other'. He concluded that he did not want to be different but he did want others to be aware and accommodate his needs. He saw people who were 'oblivious' as rude and the situation as social exclusion and oppression. Aidan had some awareness of disability activism on this occasion and made reference to this: 'it

makes me feel like a good cause like the world's not for the people with disabilities to do different things, there are some people that notice and take action, you know?'.

Aidan also objected to what he saw as the patronising attitude of a stranger who asked if he was 'alright?' whilst he was waiting for his mother. In his opinion, they did this because he was a wheelchair user and he felt they would not have said this to his non-disabled brother and therefore he would rather that they did not speak to him, 'and then erm this person's come at me and says 'alright?' and I hate that like it's obvious that he's doing it to...they wouldn't do it to my brother but they do it because I'm the way I am so it's like, you know, I'd rather they didn't say anything'.

4.3.2 Describing their disability

When asked about their disability, most pupils gave medical labels and descriptions for their impairment and/or described functional difficulties they had such as with walking or hand function. They described their impairment as a 'predicament' (Shakespeare, 2006) which they had to deal with but intended not to be ruled by. Neil has no legs and uses a manual wheelchair:

Neil: 'I get water infections....but then it hurts sitting in the chair so...I end up laying down most of the time.

GK: Right, right OK. Can you tell me about your disability and how it affects you?

Neil: Well I don't really think it does affect me a lot. I don't... I don't let it stop me most of the time. Or I try not to anyway. It doesn't really bother me.

GK: U'm hum, apart from these illnesses off school.

Neil: Oh yeah they're not really to do with my disability though... Well not my physical one anyway.'

Here Neil denied that his impairment was disabling and saw the illnesses he experienced as a side effect as unconnected. His use of the term 'disability' seemed to equate with his impairment which 'doesn't really bother me'. Other pupils adopted this attitude in their responses, e.g. David: 'the question is cerebral palsy, I've had it since I was born, it has been actually been quite easy to cope with except that I find the school work a bit harder than everybody else'.

Paul wanted to be seen as 'on the same level' as the other students, and he saw the impact of his impairment as being on the physical use of his body, though he felt other pupils sometimes thought he was 'thick':

GK: '....OK, um so tell me what is your disability?

Paul: Cerebral palsy.

GK: OK, and how does that affect you at school?

Paul: It doesn't really..... Although I have to do everything around a chair instead of on my legs, that's all, really...And everyone thinks, like because I've got cerebral palsy my brain don't work properly and so basically they think I'm thick. But I've proved to them that I'm not. I've proved to the teachers, not that the teachers thought anything, but I've proved to the teachers while proving to the students that I'm actually quite clever, where I'm on the same level as them....even though our legs don't work or something'

Paul was actively resisting what he perceived to be assumptions made by his peer group that he had a learning disability as well as having a physical impairment and in doing so, was being both an active agent (MacArthur *et al.*, 2007) and suggesting he related personally to a hierarchy of disability (Deal, 2003; Priestley *et al.*, 1999) where his physical impairment was more acceptable than a learning difficulty.

John described his disability, using medical terminology (and was actually talking about his impairment), and its functional impact. He referred to medical interventions as 'we' suggesting decisions made with (or by) someone else:

John: '.....Actually it affects my walking. So my knees are always bent when I walk. And we've been trying to...we've been trying to straighten them over the last few years'

He went on to discuss exercise and physiotherapy and how this 'invaded' his personal/ordinary life in his dreams. He introduced a pseudo-medical label in the term 'sleep moving'.

In his third interview in year 11 John mentioned feeling tired all the time, and I questioned whether this was because he now used a manual wheelchair. He disagreed and blamed 'disability' which 'saps my energy'. This perception was different to that of Neil and Ryan

since John described his impairment more in medical model terms, where he was adversely affected by his disability, which did bother him.

Ben described in pragmatic detail, relating to medical advice he had received, what his physical impairments were and how these affected him. He described the doctor's orders and his own learning needs related to his functional difficulties. He was unable to take part in contact sport, had difficulties using pins in sewing lessons and pushed around a manual wheelchair to use if he got tired.

In his second interview when Ben was in year 11 I asked him about handling pins – but this was no longer relevant to him as he did not do sewing any more. So the impairment had been specific to the lesson being delivered, and had become less of an issue as Ben got older and chose options, because he could opt out of this.

In year 11 Ben repeated some of the factors he mentioned above (no contact sports, tiredness) and was particularly keen to emphasise the importance of his wheelchair being with him at all times, though he did not sit in it very much, and tended to push it around himself. He talked about a main factor in his impairment being one of tiredness and he emphasised the 'risk' of not taking the wheelchair with him, through the use of terms such as 'would be taken under any circumstances', 'on the safe side', 'on those rare occurrences, it's nearly always taken on all the trips I go on these days'.

For some pupils, their aids, particularly their wheelchairs, were part of their identity, and something they felt they shared in common with me. In his second interview in year 11 Ben commented several times on his insistence that his wheelchair should accompany him on all trips:

Ben: '... because I remember about three weeks ago we went over to Portsmouth shopping on the ferry and on the way – I took my wheelchair because I always do out of school for long distance trips as well, maybe shopping and things, out of school.'

Taking the wheelchair in this way seemed part of Ben's identity, maybe a defining factor in his disability – it seemed to represent convenience, an emblem, signalling something more socially acceptable than perhaps a walking frame, perhaps an identity Ben found positive.

Rory also defined himself by his wheelchair:

GK: 'Yeah? So tell me about yourself a bit

Rory: Er I'm here, I'm a student, in a wheelchair

GK: Yeah

Rory: And I'm, I'm in 9D. That's it'

Paul felt strongly that he was picked on by other pupils and he perceived their uninvited invasion of his personal space around his wheelchair as indicative of their perception of him as something less than human:

Paul: 'And some people when I moved about just grab hold of my gear stick, I don't know if this happens to you, grab hold of the gear stick or grab hold of the chair and just push.

GK: Yeah. Yes and how do you feel about that?

Paul: And it's like, huh there's an organism here, you don't need to just physically move the chair, you have to ask the organism. Not just, oh there's a wheelchair, let's push it out the way. I can understand if there was nobody in it, just pull it and move it but not when there's somebody in it, you have to ask them to move.'

For Paul the wheelchair was also an essential part of his identity and an extension of himself, his personal property, not to be touched by anyone else without his permission. He recognised that I was also a wheelchair user and invited me to share my experience with him, thus demonstrating his expectation of our shared awarenesses and understandings. When other children touched his chair who were non-wheelchair users he protested vehemently at the abuse of an unequal power relationship and their lack of respect for him as a living being.

Other pupils also talked about the importance of the status of the equipment they used to their self-identity. In year 9 in his first interview John talked about his unhappiness with the speed of his electric wheelchair. He talked a lot about being bullied and felt this was 'because of my wheelchair speed' and described how other disabled pupils 'smashed straight into the side of me'. He thought having a faster wheelchair would make it easier to make friends and get rid of bullies.

By his second interview in year 11 John was in a manual wheelchair, which he preferred, he reinforced his preference for this in his third interview, later in year 11. He described his plan to get a manual chair (although before in year 9 he had talked about getting a faster electric wheelchair):

John: ‘Yeah, I just nagged and nagged and nagged [*laughs*] and then one time I just punctured my tyre and that was it and they took... they took it away from me.... and then I got to use this full time. So it was me basically,... manual wheelchair plan [*laughs*]

In his third interview in year 11 John discussed his new wheelchair and how it made him feel – more agile, building his muscles, he did not agree that it made him tired, but felt it is disability that does this. He told me how he modified his chair for appearance and speed, even though it resulted in safety issues as he became more likely to fall out of his chair. John could get things out of his backpack if he had arm plates on, and they helped prevent him from falling out of the chair, but he chose to take these off to enhance his appearance, even though this restricted his independence. He was in fact not even going to take his back pack with him, but planned to leave it in his locker. He thought having no sides was easier because he was faster, in fact faster than electric wheelchairs – faster, more agile, lighter (which is also better for transport out of school of course, being more flexible). John had switched his allegiance from faster electric wheelchairs, to light, manual ones, on the basis of self-image.

Another sensitive equipment issue relating to self-image was the use of portable computers with some of the pupils saying how much they would like a proper laptop, rather than an ‘AlphaSmart’, which is basically a portable keyboard and which was more readily available to them, and, in the school’s opinion, fulfilled the required need. These seemed to be treated rather disdainfully and were often damaged and taken away from the pupils, who then relied on LSAs to scribe for them.

One of the disabled pupils, Aidan, who was interviewed in year 9 and year 11, talked in depth about his difficulties with behaviour control, how these impacted on his identity in the eyes of others and the difficulties he was struggling with to understand himself and improve his behaviour. He reflected on his problems in primary school where he suggested he had difficulties coping with his own feelings, that he felt a loss of friendship and support, feeling let down and a loss of trust, experiencing a negative downward spiral. He

was dependent on one carer, who eventually refused to look after him, resulting in Aidan becoming stuck, permanently excluded from school and trapped at home. He went on to say how this negative experience had changed him and that he was now in a negative cycle, where he had negative expectations of outcomes. He had positive memories of starting school, but suggested school had negatively shaped him; though he also showed self-belief and being disappointed in himself and his struggle to turn things round. Aidan described how he considered the negative cycle he felt he was in at school to be grossly unfair and that he was inappropriately blamed or scapegoated by the other pupils and teachers. From a social constructivist perspective, this can be seen to be a fundamental part of his identity in the school setting, which over rode his perception of himself as a disabled pupil. He did mention in his second interview that he did not get into so much trouble out of school – reinforcing how these pupils seem to have multiple identities which vary across time and settings (Shakespeare, 2006).

In summary, these disabled pupils described their disabilities mostly in terms of the functional limitations imposed by their impairments, often insisting that these were not very significant and were ‘predicaments’ that were easily dealt with and by which they were not very bothered. The importance of the status of the aids used by these pupils to deal with these functional challenges, particularly their wheelchairs, was emphasised by several of the pupils. It would appear that certain aids such as ‘AlphaSmarts’ were perceived by the pupils as stigmatising, other learning tools such as multi-functional laptops were more valued. For pupils with significant mobility difficulties a wheelchair was essential, but again the ‘quality’ and ‘attractiveness’ of the chair was important from a self-image point of view, particularly within the social context, and the chair became part of the personal space of the pupil, such that uninvited touching of the chair became an invasion of this personal space.

4.3.3 Words to describe themselves

In the later interviews I started to ask the pupils if they could think of some words to describe themselves. Their responses indicated some personality characteristics they thought were pretty stable over time (e.g. helpful, kind, polite, bright). Neil described how his feelings and personality have been influenced by the school setting and how he presented differently now in this secondary school setting. Aidan refused to attach any descriptors to himself, recognising that there was something stable there, ‘me’, that he could not describe, but also recognising that he would come across differently to different people and at different times. Some pupils (John and Rory) saw themselves in a derogatory way, suggesting low self-esteem, though they

laughed this off, taking on board the role of class clown (e.g. annoying, 'I don't think at all', make people laugh).

Above all the pupils' self-descriptors showed that they were just like any other group of pupils in the range of attributes they applied to themselves and how they reflected on this (Harter, 1999; Rosenberg, 1986). The role of their disability or impairments was relatively small and only part of their self-perception. Their personality characteristics and feelings were seen as much more important.

Attempts might be made to simplify into binary categories the states of ability and disability, illness and health, construction of identity, however these boundaries may be crossed and can be unstable, in a constant state of flux. Marks (1999) quotes Zola (1988) as describing the experience of impairment as highly variable between individuals and within an individual over time (exemplifying this with reference to progressive conditions such as Muscular Dystrophy and Multiple Sclerosis, asthma, diabetes, epilepsy and time of life factors). As Foucault writes in *the Archaeology of Knowledge*, "don't ask me who I am and don't ask me to remain the same" (quoted in Marks, 1999, p. 125).

4.4 'THEY KNOW I'M DIFFERENT': Pupils' perceptions of difference

Although the pupils very much saw themselves in the same way as all pupils do, a core theme that emerged from the data was that of being seen as different by others or alternatively as having a sense of belonging or acceptance within the school. This was referred to in a number of ways by the pupils. For some pupils there were strong feelings of an imposed dichotomous split separating disabled pupils and other pupils in the school, with mention of there being two different races, or social classes, or of feeling like an outsider or observer. Paul described the 'able bodied students' as 'king and queen sort of thing' and felt he was singled out as different. He described how he felt normal, though a wheelchair user, but he thought other pupils saw him as being of a lower race in society. As such he tended to associate with the other disabled pupils – 'I like to stick around with my own kind'. Hence Paul's perceptions and consequent behaviours become reinforcing of the dichotomous split which he himself says is 'horrible'.

This raises the issue of whether the existence of the 'resourced disabled pupils group' creates more division than in other situations where the pupil was part of their neighbourhood class, as was this pupil's experience in primary school:

Neil: 'Like there's about 30 of us with disability. They kind of think... everybody kind of thinks that we should hang out together and not be with able bodied people. I don't know why but I think they kind of see it that way. We're not the same as them so we shouldn't do the same things as them or whatever else. But there [*primary school*] I was always kind of the same, which was good.'

This sense of being different and feeling set apart and self-conscious about this pervaded a number of these pupils' comments. Neil emphasised this sense of feeling different and set apart from the whole community of the school by using the following metaphor:

Neil: 'Um I think I've never really been a part of here, I've always been... I've always felt I've been in a glass box just watching what goes on but not really being a part of it if you know what I mean'

However for Aidan the presence of more disabled pupils made secondary school much better than the primary school from which he was permanently excluded half way through year 6. He preferred the secondary resourced provision because he did not feel so different because there were other disabled pupils and he was not 'tied' to his LSA but had several helpers. He seemed to suggest that there was a group identity at the secondary school, where he did not feel entirely different, 'the other mainstream school I was the only one in a wheelchair but here I'm one of a few'.

He expanded on this even further by describing that he found the secondary school like a 'family', emphasising a sense of belonging with his whole class. This went beyond the sense of belonging with the other disabled pupils, to include a sense of being part of the school:

Aidan: 'It was good because it's just like one big....oh, that sounds really, what's the word...really, like, funny, but like we're all one big family whereas before, because we were all different I felt, like, I was less sort of in the family of the group of people I had in my class.'

Later, he checked out that I understood what he meant by family and explained further. 'We all look out for each other, in a way'. His comments suggested he felt more able to share trust in the secondary school where he described more of an attitude of acceptance.

In contrast he described his experience at primary school where he felt a close friend and the adults turned against him, that he was not supported or understood, his friendship broke down, whilst the secondary school showed more tolerance and acceptance.

However Aidan was feeling vulnerable at the secondary school where he knew he needed to change his behaviour to avoid permanent exclusion from the school - 'I'm trying to be, not be totally different, but try, trying to be how I was when I first started school'. He talked about how another pupil, a female, non-disabled friend, was helping him to be more successful and survive in school, 'steer me in the right direction'.

Other pupils, such as Harry, talked very much from the perspective of being part of the school and accepted by others. In this context, differences were mentioned almost as privileges, supported by some of the other pupils. With some, but not all teachers Harry could leave lessons early, he had learning support assistance and he had a taxi to and from school; he mentioned that other pupils help him by signing him out of tutor at the end of the day while he left early for his taxi. Another pupil, Neil, saw this as a problem, because he missed the end of day notices and felt excluded from some activities in school as a result. He gave this as one of the reasons why he wanted to change schools.

Physical limitations sometimes prevented conforming to classroom/school rules even though the pupil did not want to be different. Some pupils found this uncomfortable and difficult to resolve. An example of this was not being able to put up one's hand to ask the teacher something (from a pupil with muscular dystrophy):

Sam: 'Yeah, but a teacher, I can't put my hand up so they'll see me, but you're not meant to say that.

GK: Why not?

Sam: Because I can't do anything, I can't put my hand up - she'll think it's rude.

GK: Oh right.

Sam: Wouldn't she so, and the teachers would think it's a bit rude just shouting out.

GK: So you're saying that you find it hard to put your hand up.

Sam: Yes I can't exactly put my hand up.

GK: So you shout out instead.

Sam: Yeah.

GK: And sometimes you get told off for that?

Sam: Erm I just... well I don't want to shout out.

GK: So sometimes you don't ask for help perhaps when you need it.

Sam: [*4 second pause*] They do ask for us to shout.

GK: Pardon?

Sam: I just struggle here.'

Sam had special permission to shout out, but he found this hard to accept, because he was self-conscious and did not want to be seen as different, preferring instead to follow the general classroom rules.

For Paul there were privacy issues which were raised by other pupils questioning the fact that the school rules did not seem to apply to him, such that his personal needs became publicly discussed:

Paul: 'But, um the teacher stuck up for me and said, if he needs sorting out before lunchtime that's he... that's his problem, well not a problem, but that's his responsibility, that's the staff's business, not to do with you. I mean I don't mind them knowing what it is but still. But you don't need every Tom, Dick and bloody Harry to.....

GK: [*Laughs*] Comment on it.

Paul: Yeah.'

In the present study many of the children commented on the perception of them as different by others or as feeling different, when they did not want to be seen as different, or perhaps they wanted everyone to be seen as different in their own way, and for this *not to matter*. An example can be seen in an issue raised by one pupil who had no legs and used a wheelchair in the resourced secondary school. In the primary school he described how he used to get out of the chair all the time, but did not at the secondary school, having been told by the occupational therapist that it was not appropriate. This 'kind of bugged me at first', 'it kind of made me a bit mad because...that's how I'd always got around, I used to hardly ever use my chair and now I kind of always use my chair': what was the norm for this pupil was no longer acceptable and having to change that behaviour served to underline their difference and otherness, and perhaps suggested only a conditional 'belonging' – not as they were, but only if they changed and conformed.

This pupil went on to say that he got out of his chair at the disabled youth group PALS where he had grown up with the other people, that it did not bother him being on the floor and he felt that it was a frustration of being at the large secondary school that he 'can't do what I used to do at B and get around the way I used to', thus he felt more 'able' at PALS with disabled peers where he could be himself. Subsequently the family were seeking alternative placement at an independent special school for children with physical disabilities.

Such awareness of being made to feel different has been noted by other researchers (see section 1.13.1), who have variously argued that this may be due to the children's impairments (Morris, 1991; Thomas, 1999; Lightfoot and Sloper, 1999) or to more contextual elements surrounding the children such as the cultural and structural aspects of the school setting, the adult discourses used around them and their relationships with peers (Connors and Stalker, 2007; MacArthur *et al.*, 2007; Davis and Watson, 2001). The examples above support this social model interpretation – where the pupils' explain their experiences in terms of the settings they are in.

4.4.1 Being part of the class

Issues about being included in lessons and receiving the curriculum alongside other pupils were key to the sense of belonging in the resourced school. A number of pupils commented on not being properly included, whilst others noted the efforts of some teachers to meet their needs.

Paul mentioned being 'forgotten' and not catered for in the lesson planning, and feeling this might be seen as having a negative impact on the rest of the class:

Paul: 'So what's the point and they... and sometimes they forget that that they have disabled people in the classroom 'oh, let's do this, oh, wait, sorry we can't because we've got a disabled person in the room'

Paul noted this difference in that he was not able to work with students he would like to be working with, because they did not want to work with a student who was disabled. Paul would have liked them to work with him so they could see 'what the real Paul is like'. Instead he felt he was perceived as 'a disabled child' and hence 'different' and therefore to be avoided by most 'able bodied students'.

Another pupil, Fraser (who mentioned having sisters who were involved in competitive athletics), noted the efforts of his PE teacher to meet his needs in the lessons. Fraser was ambulant but had walking difficulties and he described how his PE teacher tried to ensure he was included, sometimes this involved using a wheelchair:

Fraser: 'It's like with PE, my um... my PE teacher, he tries to involve me with it all the time so that's quite good, instead of just saying, oh, there's some stuff, you go off and do your own...like do something, he tries to involve me in what they're doing. So I quite like that, like when we're playing cricket or something he tries to involve me....if it's other things like, um [*13 seconds*], I suppose with, like running and doing the running, like athletic things they do every now and again, he says, he like um says that I can do it, I can just go around the track in my wheelchair....And um that's quite a good way... because sometimes I'm just sat there otherwise and it's like... so I'm there for an hour and it's like....So sometimes I think oh great, but other times I'm like just there [*laughs*].

GK: So when you're sat there would you do anything about that?

Fraser: [*8 seconds*] I suppose when I'm sat there, I'm like cheering other people on and I suppose trying to get involved but not having to do... do much.'

Even with positive encouragement and support there were still times when Fraser felt left out and an observer, rather than really involved. He later talked about not always being with other pupils with disabilities, 'sometimes I don't mind but then other times I don't want to be....sometimes I'm just like, I actually want to go off and like be with other people and do what they're doing'.

He talked about how he negotiated with his PE teacher what he could and could not do, and sometimes the teacher told him 'I don't think you should do this', which, on the whole Fraser accepted, though he occasionally felt 'why can't I do that?' – some frustration was experienced which Fraser found hard to express, especially when it was something he would have liked to do. However he went on to say that he was getting his own awareness of what he could and could not do, 'sometimes I try to do it and I know when to stop, I just know when like, when to not do something' and therefore could make his own decisions in

this respect. He stressed the importance of the teacher's understanding and trust for this to work.

Another pupil, Neil, felt he was treated differently by teachers because of his physical impairments and was seen as not able to do things rather than the teacher exploring what he could do:

Neil: 'I think sometimes like, um it depends what subject really, like in more practical subjects like dance and drama and that kind of thing, I think sometimes, you are treated differently and PE, but then sometimes like... most of the academic ones it doesn't make any difference.

GK: So how are they treating you differently in those um more practical subjects?

Neil: Um I think they don't always see... they may sometimes see what you can't do and then they don't give you always an opportunity to do what you can do.... Because they kind of judge you on what they think... what they think you can do rather than ...what you know you can do. If that makes sense.'

He also mentioned a lack of understanding by teaching staff of how to adapt the lesson to meet his needs as a disabled pupil, and felt that instead he had to know how to fit in – he had to be the expert on his own needs: 'And sometimes I think they kind of expect you, like it comes with a handbook whatever you know, what to do with the chair and you know, where you ought to be....And a lot of the time I don't kind of know what I'm doing so....'

The comments made by some of the pupils in the present study suggested that they had an awareness of their own needs in comparison with their non-disabled peers but that they did not want to be viewed as different or treated differently, particularly in negative ways (also observed by MacArthur *et al* , 2007). This sense of 'being made to feel different' was mediated by contextual elements such as their relationship with others, particularly peers, and cultural and structural aspects of the school setting. Most pupils dealt with these experiences by remaining positive about school (a few were more negative) and becoming active agents, through resisting the disabling experiences, challenging low expectations, taking the initiative, informing teachers or other adults, expressing their views, using humour (as also found in MacArthur *et al* , 2007; Connors and Stalker, 2007; Watson *et al.* , 2000). In this study one pupil believed he had convinced his teachers he was cognitively

able; another child took the initiative by organising a marathon of disabled pupils for Sports day to raise money for disabled children overseas.

Being treated differently and being questioned by others about this, a lack of understanding from non-disabled peers, feelings of rejection because of these differences, not being able to take part in a lesson, and having to sit and watch, or work with a group of other disabled pupils whilst wanting to be with the majority of the class were all issues expressed by the pupils, relating to experiences of 'difference' or 'otherness'. Allied to this was a sense of 'not being good enough' which was mentioned by several of the pupils, as by Neil above. These factors had led to a sense of not belonging for some pupils in the resourced secondary school, reinforced by Neil's use of images above such as being 'in a glass box' and 'we're in a kind of race' (i.e. a different ethnicity to the majority of pupils).

4.5 'SOMEONE THAT'S THERE': The importance of friendships

A core theme relating to friendships was identified in the analysis, which was an issue of great significance to the young people. A number of categories emerged within this theme:

Other pupils

Other disabled pupils

What makes a good friend

Forced to change tutor groups

Seeing friends out of school

Leisure activities with friends

Smoking and girlfriends

4.5.1 Other pupils

The disabled pupils' views of the other pupils in the school showed a wide range of variance. Some were very positive, like Harry, who saw other pupils as 'very nice, very helpful'. Rory referred to a list of friends, some of whom were disabled, some non-disabled. He referred several times to one particular non-disabled friend who helped him with his spellings in class when there was no LSA and whom he found very funny. Other disabled pupils, such as Fraser, saw more polarity in the reactions of others: 'some people at school treat you like they don't want to know you but then others want to help you'. A number of the pupils seemed to equate friendship with being helpful in this way, a finding noted by other researchers (e.g. Watson *et al.*, 2000).

Paul differentiated between pupils who knew him, who were fine, and those who did not know him, whom he found rude and overly inquisitive:

Paul: '... the people that know me are alright but the people that don't know me are like, why are you in a wheelchair, why do you need it, why... I don't need the Spanish Inquisition, there may be 50 questions about why I'm in a wheelchair. Last year I was out on the school field and someone approached me and said 'how do you go to the toilet?' And I'm like, erm, personal question. I mean if another disabled asked me, sure I'd be fine with it because they know I have difficulties going to the toilet, all disabled people do, they need people to help them go to the loo, but normal people... oh I used that word again... able bodied students come up... when they come up to me and go how do you go to the toilet? It's like, uh. But if it's someone that I've known that's an able bodied person and I can easily talk to them, say if they are [pupils' names] I just answer them, either I need to go to the loo or I use a bottle, depending on which one it is... But when it's other people... and it wouldn't be so bad if I told them and then they didn't laugh about it sort of thing... I mean I've had that happen to me before. They keep pestering me, 'How do you go to the toilet?', 'Huh, that's a personal question I'm not willing to answer that' or 'I'm not able to comply' 'No come on Paul' and they... so I tell them and they laugh about it so I'm like...

GK: Why do you think they laugh?

Paul: It's sort of an embarrassed laugh sort of... how dare they ask the que... it's like, oh I wish I didn't ask now sort of thing, well don't ask then.'

So for Paul, the personal questioning was acceptable if the other pupil was known and a friend, but not by a stranger, which seems to be a yardstick that everyone might use, but which gets ignored for the disabled child. Paul felt he had been made to tell - 'so I tell them and they laugh about it'. Paul felt that his feelings were discounted and he was angry and ready to assert himself. For Paul, his experience represented the power imbalance and unequal status between him as a disabled pupil and the other non-disabled pupils (Foucault, 1967) and was evidence of the visually stigmatising effect of his impairment (Goffman, 1963). Neil saw other pupils as viewing the 'disabled pupils' as all the same, wanting or needing help:

Neil: 'Um I think they kind of in a way get brainwashed andhow they think we should be, how other people think you should be treated. But then I think they kind of see it as kind of, like obviously we're all different like, so how one person might want to be treated in a chair is different to how another person might be, but they kind of think... think like we're all the same so.... I don't know, I just get a bit... I think they're kind of just brainwashed to what... what to do to help and that kind of thing that sometimes some people want, but some people... other people don't want or need, or whatever else they want or stuff like that.'

Instead Neil suggested everybody is different, with individual needs and wishes. This pupil also commented on the difficulty of making friends, due to his frequent illnesses which led to absences from school.

Ben referred to having friends two years younger than himself, and for this pupil it became apparent later in the interview and when I interviewed him in year 11 that he related in an adult like way to other (usually younger) children, rather than having true friendships with them.

In year 11 I asked Ben about what he did at home in his free time. He made it clear that he needed to rest in the evenings, so sat and relaxed, watching television and it appeared that the weekends were determined by the adults he lived with (his grandparents) and seemed to revolve around shopping.

When I asked Ben what his hobbies and interests were, again these seemed led by the adults he lived with, rather than usual teenage preoccupations, and were watching the soaps and wrestling on the television and collecting memorabilia from these. As he talked it felt like one was listening to a repetition of his Nan's dialogue with phrases such as 'it's nice as a piece of memorabilia, you know', 'he put it up there for advertising purposes'. Ben showed insider knowledge in his areas of interest, mentioning Newton and Ridley in relation to Coronation Street, and 'it weren't the top trained wrestlers, it was the academy people' – again, knowledge gained probably from the adults he lived with. He described recently buying himself 'the Queen' DVD which seemed an unusual choice for a teenager and commented how he liked to watch the extras first on a DVD, about the making of the programme. Ben had no contact with young people of his own age out of school and this

was apparent for several of the other disabled pupils (e.g. Harry, Rory) and consequently their age appropriate social experiences were limited.

4.5.2 Other disabled pupils

Apart from a few pupils who had issues about being perceived as belonging to the 'resourced disabled pupils group' generally the disabled pupils liked being in a school that had other disabled pupils around.

GK: '....And how do you feel about being with other disabled pupils in school?

Paul: It was... yeah it's fine because they know what is wrong with... what is my disability, they know all that, they're not going to pick on me because I'm disabled because they are in the same boat'he, he's in a wheelchair let's pick on him... Well that's the way I see it, I don't know obviously but that's the way I see it.'

Paul appreciated the empathy he felt other disabled pupils had, whilst recognising that their impairments were different. He labelled the other pupils as 'normal' and 'able bodied' and felt picked on and treated differently by the other pupils and concluded 'they're all blooming disabled pupils that are my friends'. However it appeared that he felt forced into this and would have preferred it to be different.

Aidan liked the fact that there were other disabled pupils in the resourced secondary school compared to being the only wheelchair user in the primary school from which he had been permanently excluded.

For David, his most successful friendships had been with other disabled pupils. He first referred to these friends and then later described how he had tried friendships with other pupils, which did not seem to develop, so he returned to 'people who have my problems, like you know, disabled kids' For this reason a lot of his friends were in different year groups and so left the school before him.

At the resourced secondary school a number of the disabled pupils appeared to relate more to other disabled pupils than the other pupils in the school. In his first interview Ben volunteered more about friendships and the importance of the Thursday club. The friends

he referred to were also disabled pupils and Ben used the phrase 'he's disabled as well' to describe his friend (a much younger pupil).

In his second interview in year 11 I became more aware of how limited Ben's friendships were and how his acquaintances with other children were predicated on being helpful – he adopted the role of the adult towards the child rather than a symbiotic relationship, as though imitating his own relationships with those (adults) who supported him. He described himself as helpful:

Ben: 'I'd say I was, because I help a lot of the students around the school, a lot of the PD [*physically disabled*] students and a lot of the PD students around the school, so I'd say helpful was one and erm..... [23 *second pause*] helpful and kind I suppose, like you

GK: mmm, right, helpful and kind?

Ben: Yeah, they're the words I'd use to describe [*myself*]

Ben's reference to being kind like me, suggested further evidence that he was following adult role models in his relationships with other pupils.

For one pupil, Neil, making friends had been difficult at the resourced secondary school, because of the dependency of another disabled pupil who had transferred with him from primary school. Considering this was now year 9, this dependency seemed to have had a big impact on this pupil's inclusion into the resourced secondary school, limiting his opportunities to develop and sustain new friendships in the school. A significant element of this seemed to be the isolation the other pupil felt in the resourced secondary provision, compared to the primary school.

Other researchers (e.g. Watson *et al.*, 2000) describe some disabled children as associating with 'their own impairment group' at school as an active choice, for example, for communication reasons. In the present study, the reason appeared to be more circumstantial, in that there was an imposed social construction of the 'PD resource' to which these pupils belonged, whether they chose to or not. In fact, more notable was the active resistance of some pupils to be categorised within this group, e.g. Fraser, Aidan, and potentially, those pupils who did not pursue the invitation to take part in this study.

4.5.3 What makes a good friend

During our conversations I asked the pupils what they thought made a good friend and they were able to define a number of characteristics, such as helpful, dependable, caring, kind, loyal, good personality, enjoys having a laugh, someone to talk to, someone who is there for them. They all thought they were good friends with these qualities too.

Aidan saw some 'friendships' as the other person using the disability to secure advantage, rather than liking the person being so used, i.e. conditional friendship. To Aidan a real friend wanted to help because they cared for the other, i.e. unconditional friendship:

GK: 'So what makes a good friend for you?

Aidan: Someone who is not just with me to like, get out of lessons, because obviously I leave a few minutes early so I can go downstairs and that, because I feel, like, the person who I had in the other mainstream school was just with me just to get, like to be able like, get out of lessons early. But I think a good friend would be, like, someone who is actually with, friends with, just to help me, not just for their own benefit.'

In year 11 at his second interview, I reminded Aidan what he thought made a good friend in year 9. His immediate reaction was to not agree with what he said before, but then his new definition built on his previous one, emphasising his own agency – he is the active agent, the friend helps him to do this, to achieve autonomy, and then he added two more elements.

GK: 'And you said, 'A good friend is someone who is friends just to help me, not just for their own benefit'

Aidan: See I don't agree with that now

GK: What would you say now?

Aidan: Someone that kinda stands by yer, helps yer, tries to help you help yourself and can have a laugh with yer and is nice.... Yeah'

He seemed unsure whether he had friends like that. He eventually admitted that moving tutor groups encouraged him to mix with other people who had been better for him – here he was still working through an issue which I discuss below.

4.5.4 Forced to change tutor groups

At the resourced secondary school the pupils were placed in tutor groups in year 7 and then remained with these groups throughout their five years at the school. Aidan had talked extensively in his first interview about the behaviour problems he experienced at school and his fears of being permanently excluded from the secondary school as he had been from his primary school. He described how a non-disabled female friend was encouraging him and how he needed more 'sensible' friends.

In his second interview in year 11 Aidan discussed how he was made to move tutor groups during year 9; he claimed not to understand or have been consulted about this and appears to have resisted the move by sticking with the other group for a while, showing active resistance. He said he was now not 'ashamed': not bothered by the experience because he was leaving the school soon, though his demeanour and the tone of his response suggested that he had been bothered by it for nearly two years.

Clearly moving tutor groups is a strategy that a school might use with a number of different pupils, for different reasons, not relating to disability issues at all. Aidan's 'disability' may have aided his survival at this resourced school, because of the lack of alternative options for the local authority who were responsible for his education because he was a child with a statement of special educational needs; at no point did Aidan seem explicitly aware of this.

Transitions to new schools, classes and tutor groups are known to be difficult times for children and young people (Galton, *et al.*, 1999; Tobbell, 2003). In addition, here the school used this strategy to increase adult control over difficult behaviour, Aidan felt a sense of loss and embarrassment at having been moved in this way. He explained that he had felt a sense of belonging to this peer group: other pupils remembered that he belonged to this group. Aidan found it hard to leave that class and go to another one where the friendship groups were established and he was not part of it. Aidan felt he was excluded from the friendship groups in the new tutor group because these had already been formed over the previous three years. Aidan reported that he was not consulted, the change was instigated by a letter from school while he was off school, ill. Aidan was unable, or unwilling to specify a reason why the school would have done this so I reminded him of something he said to me which suggested he, himself, was considering he needed more sensible friends at this time, but Aidan wanted the sensible friends to be in the same tutor

group. This lack of consultation and joint problem solving with the pupil is reflected in other experiences described by some of the disabled pupils in this study.

4.5.5 Seeing friends out of school

All the disabled pupils said that they seldom if ever saw friends out of school, except through an organised group such as PALS or at the school's after school club, called the Thursday club. This is a finding noted by other researchers (e.g. Connors and Stalker, 2007; Skar, 2003) though these researchers attribute it to reasons other than those given by the pupils in this study (mainly distance from school), for example being excluded from social groupings at an early age resulting in not establishing deep bonds of friendships (Skar, 2003, p. 641) – most of the pupils in the present study had neighbourhood friendships in their primary classrooms.

Several pupils had already commented that they had lost touch with their friends since their transfer to the resourced secondary school, and many of them had resented and regretted this, feeling they had been forced away. They were unable to meet up with the new friends they had made at the resourced secondary school because of the distance they lived from the school. Fraser had rationalised his position, and although saying that he saw friends out of school very infrequently, this did not seem of too much concern for him. He agreed that the reason for this infrequency was the distance between where he lived and where his school friends lived. He still managed to keep contact with some friends from his previous school, with whom he felt he had a shared understanding.

It was apparent that I had hit on a very pertinent issue when I asked Aidan in year 9 about seeing friends out of school. Aidan had problems seeing friends because of money, his behaviour and his parents not being confident he could cope.

GK: 'I see, yes, right. Do you have a chance to see any of your school friends after school?

Aidan: Ah, this is something.

GK: Right, go on tell me.

Aidan: I've planned Christmas shopping, right, but I can't go because, one, right, I need to behave so I can get some money and two, my mum just, I don't think she trusts me, because like, my friends and that, I don't think....'cause I would love to be able to go down town with a few of me mates and just do what normal people do. 'Cause like, half the time, the

only time I see people that are here are during school time and I can't exactly do what I want to do during school time, can I?

GK: So you would like to be with your friends more out of school?

Aidan: Yeah.'

Aidan shared his planning of how he might achieve such outings with me. One problem he foresaw was the over-protectiveness of his mother who did not think he could cope by himself, with a friend 'in public': 'I can do toilet for meself and that, but my mum, she wouldn't want, trust me doing that in public'. He described how he could get a non-disabled female friend to help him. Achieving such independence to go out with his friends was a major ambition for Aidan, and he thought other disabled pupils would share this ambition - 'like most of the kids that are disabled – they probably want to do that' - though none of the others expressed this as forcibly as him. He used me as a resource, in an unexpected question addressed to me, whilst we were talking about learning and lessons.

Aidan: 'Do you know any one, like, obviously you see other people, but do you know any one that's actually done what I want to do? Like, just go out and socialise with people I know, that are obviously same position as me?'

There followed a discussion about this with the following conclusion, 'I just want to do what normal teenagers do, at the end of the day'.

In his second interview in year 11, I was interested to discover that Aidan physically carried out the dream of independence and spontaneity that he had so craved in year 9, but not without the cost of getting into serious trouble. He described an occasion when he had left school with his 'mate' without telling anyone or phoning his mother, which caused a great deal of trouble when his mother contacted the school and the police. A bus driver had remembered him, and he had finally been tracked down to his father's flat (his father had been at work). Aidan had got into big trouble for not telling anyone, but he had actually managed to do it successfully. Whether he had genuinely forgotten to telephone his mother, or whether he was determined not to be stopped was unclear – he now appeared to genuinely regret his actions and wished he had let her know to prevent the trouble which ensued. The protectiveness of the adult network around Aidan sprung into action – clearly his parents were very concerned about his safety and involved the police and the public bus companies which was perhaps more than they might have done for a non-disabled teenager

(he was 15 years old). Interestingly, perhaps because Aidan was a wheelchair user he was remembered by a bus driver and eventually found.

Since this incident the school was restricting Aidan more now. On the first occasion the fact that the teachers had not tried to stop him might be considered to be an accolade to the school in that a youngster in a wheelchair was considered unexceptional and that a year 11 pupil should be responsible for themselves whether in a wheelchair or not. However his mother had changed her views and Aidan was experiencing more freedom on non-school days. Through taking risks and demonstrating his ability to be autonomous, with the help of friends, Aidan had achieved the ambition he described in year 9.

David was another disabled youngster who had very few social contacts out of school and whose main source of companionship was from within the family. He spent a lot of time with his younger brother, who was also disabled, being partially sighted, and he found this relationship difficult and annoying. David described how an old friend he would like to see lived close by, but was not considered to be a good role model by his mother, and other friendships had dropped away because he went to a different school. He mentioned that he spent a lot of time in his room and when he went out independently, it was to visit his Gran with his brother. There were a number of factors inhibiting David's social network. Having been held back a year and then changing schools to the resourced secondary provision, he had lost contact with friends he had at primary school. In addition his mother was protective of him and discouraged relationships with children who lived locally of whom she did not approve.

4.5.6 Leisure activities with friends

The Thursday club, which was an after school club in the attached youth wing of the resourced secondary school, specifically for the disabled pupils and any friends they wished to bring, seemed to be of considerable importance to most of the disabled pupils at this school. They had all been to it at different times in their school career and it took on particular significance for some of them, who had very limited alternatives for socialising in any other way. Another frequently mentioned source of positive identity and experience was the PALS (Partnership for Active Leisure Scheme charity) activities, which disabled pupils could attend with non-disabled friends from school as 'helpers'. The pupils varied in when and how much they engaged with the Thursday club and PALS – for some they had always used it, others picked up on it late but were now enthusiastic, others seemed to grow out of it or never engaged as they preferred going out with non-disabled friends

without the support of the club or adults. For some pupils these organised provisions were the only social contact with peers outside of school that they achieved.

John talked about his best friend Oscar, whom he called able bodied, going ice skating with him through the PALS group. They did not have equal status and John recognised this, and seemed to have some ambivalence about it - 'He was one of the helpers though'. It is possible that John felt special because the group was primarily for him, and Oscar was only able to go because he was John's friend, and able to attend as his helper. Alternatively John's dependency and potentially perceived inadequacies might be reinforced because 'helpers' were required and attendance was exclusive rather than mainstream. This raises issues about what messages are being given through such organised activities. If John was able to attend these activities with friends without having to be in an exclusive group, perhaps with an inclusive youth club, this might make a significant difference to perceptions of him as a disabled person. However some researchers have argued that both options should be available (e.g. Lightfoot *et al.*, 1999).

In year 9 Neil also mentioned PALS as a significant part of his leisure time. He also mentioned that he had a carer who supported these activities so the young person was not dependent on their parents (and, presumably to give the parents respite). This freedom from parents was important from the young person's point of view, 'when you get older you don't really want them hanging around'.

Later I asked Neil if he took friends with him when he went out with his carer:

GK: 'Do you take other friends with you?

Neil: Um I can't take other people with disabilities with me.... Because there's only, I don't know, something about they can't be responsible for other people but then I don't really go out with my friends because I don't think they'll like another person hanging around. So sometimes we meet up with um Paul and he's got a carer from the same agency so we sometimes meet up together and do stuff.....Which is good.'

This underlines the social restrictions these young people have to tolerate because of their physical 'predicaments' (Shakespeare, 2006) and the limitations these place on their experiences. Again, there is a glimpse of how these restrictions are reinforced by social policy issues in the supportive provision available to them.

Fraser shared a passion for cars with his father and enjoyed this leisure activity out of school and intended to take this forward as his choice of career in the future. He and his father attended track and car racing together, and went to car shows, when his father 'is not doing athletics with my sisters'. Most of the disabled children spent their free time with adults or by themselves in their homes.

A number of the pupils I interviewed mentioned a fund raising wheelchair marathon that was being organised by one of the most severely disabled pupils in the school. There seemed to be a lot of support for this with it being seen as 'a good thing to do'.

Fraser: '....it's like um, at the moment, coming up soon there's going to be like a wheelchair marathon that people in this school do to raise money for char... charity, to bring children over and like um... children over from poor countries to get them treated over here and have them over here for a couple of days to... like people from Africa, bring them over and get them treated with like medicines and get them well and, like take them back over and I suppose, try and help them there as well.'

This could be perceived as an interesting 'buying in' of the disabled youngsters to some extent to the 'tragedy' model of disability and need and may be viewed as 'ensuring the individualisation of the social in order to further mystify the real socio-political issues of disablement (Oliver, 1990)', (described in Darke, 2003, when discussing what he sees as the demise of the Disability Arts movement). By supporting such mainstream charity events, the pupils may be seen to demonstrate complicity in upholding the institutionalised oppression of disabled people, rather than campaigning for their rights as a subjugated minority.

4.5.7 Smoking and girlfriends

It was particularly noticeable in the interviews with two of the year 11 pupils that their concerns extended into more serious areas of teenage conflict with parents and school (Riesch, *et al.*, 2000; Smetana, 1989; Hanson, 1985), not connected with their disability, though this had an impact for them in terms of their choices and independence. In his third interview John talked about adolescent issues – friends smoking and girlfriends, though he was reporting the experience of his non-disabled friend. He mentioned that he had decided not to go to the prom because he thought he might get into a fight with another (disabled) pupil and he was still struggling with the aggressive anger he had referred to in previous

interviews towards this pupil. He mentioned that he did not have a girlfriend any more, then went on to tell me about some trouble he had been in at school over downloading inappropriate material about 'girls' from the internet. As a result of this he was excluded from school for a day and received extra punishments at home, not being allowed to record anything, having existing recordings 'crushed' and not being allowed alone in his bedroom any more because he had been on the internet there. John was shocked to be excluded from school. In year 9 he had talked to me about how he felt bullies should be excluded from school, except the ones in wheelchairs and he seemed surprised to have been excluded because of this. However, this was an example of *not* being treated differently because of his impairment.

However John's 'crime' may have been discovered because of his vulnerability as a disabled child in school because other boys in his class had got hold of his memory stick and he could not get it back. This raises issues about bullying, which I will now address.

4.6 'YOU HAVE TO ASK THE ORGANISM': Comments about bullying

Several of the pupils referred to bullying issues which arose in school. David mentioned that he'd 'attracted a couple of names around here' though he insisted he sometimes found this funny. I am frustrated that I did not explore this further, e.g. asking him what the names were/ why he thought they were funny, etc. He did not think this was bullying, whereas another child might have.

Rory mentioned bullies as a bad thing about coming to the secondary school. I asked him to expand on this, but as the interviewer I had to push quite hard and use closed questions since open ones did not get a response. Rory saw making new friends as the good thing about coming to a large secondary school and bullies as the bad thing. After much questioning he described a bullying situation he had experienced and how it was dealt with by his mother visiting the school.

Paul made reference to his identification with other disabled pupils in the school because 'they're not going to pick on me because I'm disabled because they are in the same boat'. In contrast he suggested, 'all the normal, um able bodied students like, see he, he's in a wheelchair, let's pick on him'. Another pupil, John talked a lot about bullying, in all three interviews I had with him, beginning with his own perception of being bullied and having nightmares as a result in year 9. At that time he used the term 'flamed up' to indicate how things had got worse in recent months. 'Flamed up' is an emotive word, indicating a

chronic situation which was getting worse after attempts to stop it. John talked about a group of year 9 boys, involvement of the head of year who gave detentions and excluded one of the perpetrators, but that the bullying was still ongoing. John attributed the bullying to his inferior wheelchair speed, he used the term 'disabled' to refer to two of the boys, also wheelchair users, who 'just come speeding up like thunder', again, an emotive phrase producing a dramatic and impressive effect, which suggested envy by John who, in his opinion, needed a better wheelchair. John suggested they were 'fighting' with wheelchairs and the outcome of the collision was that he needed a new control box but he wanted to fight back and damage the others' wheelchairs.

John seemed to have been vulnerable to bullying throughout his school career and when interviewed again in year 11, began to talk about 'fighting back' as a way of dealing with the bullying he perceived. From what he told me and the fact that references to bullying predominated in all his conversations in three interviews in year 9 and year 11, this had a significant and lasting impact on his school experience.

With the later interviews I asked pupils about bullying directly, telling them that it had been mentioned by other pupils. Fraser responded that he had experienced bullying and that he tried to ignore it unless he had a witness, but would report it if it 'really annoyed' him. He saw it as something stupid, and ever-present – he mentioned he felt 'lucky' that the bully moved away. Neil, talking about the impact of bullying from another pupil, which led to a change of tutor groups, commented:

Neil: 'Kind of, I don't think I trust people in the same way as I used to because we were really good mates, well I thought that anyway so... You don't expect mates to do that so I don't think I trust people....the way I used to.

GK: Anything else?

Neil: I don't think I let, like people get close to me anymore because I don't let people in anymore, I don't think. I don't know if I'll always be, like or whether I'll get... grow out of it but....I kind of don't let people get close.

GK: So it obviously upset you a great deal.

Neil: Yeah it did quite a lot, it did.'

Bullying was an issue raised by several of the disabled pupils and although having been reported to and 'dealt with' by the school it continued to have huge significance for them when they reflected on their experience of school. Some of the pupils tried to ignore it or to share the laughter, others were angry and aggressive in response. One or two of the disabled pupils were accused of being bullies themselves, by other disabled pupils. The vulnerability of the disabled pupils can be exacerbated by their physical limitations and their visible differences, and there were examples of this happening in the pupils' accounts. However, there was also evidence of assertiveness and retaliation, sometimes equally inappropriately (as found by other researchers, e.g. MacArthur *et al.*, 2007).

4.7 'A NEW CHALLENGE EVERY DAY': Perceptions of school

Most of the young people I spoke to felt, on the whole, positive about the resourced secondary school - they were in year 9 and were now settled. They talked about it being nice, with helpful LSAs, and teaching staff. A few of the pupils were less positive, with one actively seeking an alternative placement, his parents taking the local authority to tribunal to achieve this.

Paul had a lot to say about feeling different at school and lesser to non-disabled pupils, 'I feel like it's a kind of racism, I'm not allowed to be with normal people', associating only with other disabled pupils, yet still, being at school was important to him and his comments underlined the restrictions he experienced at home, 'I just enjoy the time at school. It's easier than being at home all the time'.

John appreciated that the helpers and teachers had better knowledge and understanding at the resourced secondary school because there were more children with cerebral palsy, (i.e. other pupils with the same medical label), though he pointed out that they were not as unique as him, since he had nearly died of chicken pox when younger. Aidan preferred the secondary resourced provision since he did not feel so different because there were other disabled pupils and he was not 'tied' to his LSA but had several helpers. He seemed to suggest that there was a group identity at the secondary school, where he did not feel 'entirely different'. He also mentioned that it was more accessible.

Many of the pupils commented on the differences between the large secondary school compared to the smaller primary school. They noted its intended accessibility, though sometimes access became an issue, for example when the lift was not working, which resulted in the pupils working separately from their classes:

Ben: ‘...because if the doors won’t close it doesn’t go any where. It stays where it is. And if that happens we usually work in the library’

When this happened, effectively the disabled pupils became segregated from their peers and became further disadvantaged by not having access to the teacher input and guidance.

For the three pupils whom I spoke to in year 11, their views had become more polarised but there was evidence that they were already distancing themselves from the school, preparing for the changes that were imminent in leaving school and moving onto college. Ben talked positively about his perception of school and in the second interview in year 11 he tried to explain that school provided him with a busy atmosphere that he enjoyed:

GK: ‘What do you think about, of school generally? You know, how is it for you?’

Ben: I find it very enjoyable. I find that when I come in, in a morning, yeah, I find it a new challenge every day, you know, ‘cause I’m met with erm, you understand what I mean, I’m met with challenges every day in life, aren’t I?

GK: Would you like to say a bit more about that, what do you mean by that?

Ben: There’s very little at school, and when I say very little, I mean, very, very, very, very little at school that I don’t enjoy... and erm, yeah, I enjoy coming to school

GK: Mmm. Can you give me an example of a challenge for you?

Ben: Well I wouldn’t, I wouldn’t say a challenge... I, because every day at school it’s very busy for me, you see, and that’s what I enjoy ...the busy, lively atmosphere. That’s what I mean when I say a challenge

The term challenge was used positively and Ben was quite insistent that he enjoyed school. Being busy at school was what he means by a challenge and, together with Paul, this was a major attraction of being at school, implying that life at home for these disabled children was very restricted.

4.7.1 Relevance of the curriculum

For Rory, school varied from good to bad depending on the subject matter of the lessons, suggesting that the relevance of the curriculum was an important factor. He preferred practical lessons such as ‘Tech’ and disliked French. Paul too had strong personal views on

the curriculum, objecting to religious education because he was not religious and to PE because 'we're not going to be running around'. It is interesting that he linked these two views together, not discriminating between what for him were individual preferences, rather than the first being an opinion and the second being a 'special need', which is perhaps how an adult might view them. Exposure to different religious ideals, to promote global understandings and debate, may be considered an appropriate educational objective, even if the child objects; however, researching different sports may not fulfill the aims of PE lessons.

Paul wanted his individual needs to be taken into account and he did not see the PE curriculum as suitably adapted for him.

Paul: '.... And last year it was really annoying but I found it quite good at the time because they used to send me off to the library to research about the sport that they were doing.... And I used to give it to him, but now I've thought about it, I mean it's pretty nasty, they shouldn't really do that.

GK: No, it's not giving you exercise is it?

Paul: No.'

So Paul highlighted the inappropriateness to him of what the PE teacher had devised for him to do as a substitute for taking part in the lesson. Pupils who cannot take part in lessons want teachers to make constructive alternative arrangements, such as using the time for physiotherapy or catching up on another subject, and individualising this depends on the teacher listening to the views of the pupil (Lightfoot, *et al.*, 1999; Skar and Tamm, 2001 also note this finding). Fraser also supported this view in his comments about PE, reported in 4.4.1 above.

Ben in his second interview in year 11 discussed how he lost out on his work related learning placement at college during year 11 because the course never got going, being cancelled on a weekly basis and he was never consulted about this, or offered an alternative, and instead spent this part of the week, for a year in 'learning support'.

Ben was confused about why he lost his experience at college. It is noteworthy that on a subsequent college course his grandfather used to take him there in the morning, and then he would go back to school on a bus, and then get a bus home, even though the college was

halfway between home and school. Also noteworthy was the fact that pupils were often supported by their family in this way, and if this was not available for a variety of reasons, this limited their opportunities considerably. Transport was an ongoing issue. Ben lived almost next door to another college, but the school did not link with this one on a work related learning programme. As a result of his experience in year 10 at the more distant college, Ben planned to attend this post-16, even though it was further away. This had implications for his social contacts, which again will be outside his immediate neighbourhood.

4.7.2 Difference in teachers

Pupils mentioned particular teachers whom they liked – John referred to having a better head of year and Fraser mentioned a PE teacher who particularly tried to include him. This variation in teachers was mentioned by other pupils too (Harry, Rory):

Paul: ‘And um the teachers know what I need, they always blow up the work, there are a select few people that don’t but most of the time on the whole they are alright at doing that.’

Other pupils mentioned variations in teachers in accommodating to their needs, but did not seem quite sure why this would be:

Harry: ‘Some teachers let me go five minutes early, some people don’t, some teachers like, it’s quite handy.

GK: Right, so some teachers would let you do that and some don’t let you do it?

Harry: Yeah.

GK: Is that a problem, or...?

Harry: No it’s not really, but there’s usually a rush at break times and lunch times.

GK: So it’s helpful for you if you can go earlier, is it?

Harry: Yeah.

GK: So why would some teachers not let you do that?

Harry: Because, in case....can’t remember now....they want, they want me to go with the rest of the class.

GK: And why would they want that, do you think?

Harry: It’s like.....we stick to....I can’t really remember...

GK: Stick together?

Harry: Yeah, we stick together.'

It can often be difficult for these pupils to cope with such inconsistencies across teaching staff.

Other pupils took a more active stance in objecting to what they saw as the lack of appropriate differentiation in some curriculum subjects:

Paul: 'They're alright, but there are some teachers that don't think of disabled people, the history teacher set us a project and he wanted us to research about World War II.... And also bring in a model, bring in a model and I thought ah... So again I ended up sitting around, if I was physically able to do this, then I would have done blah, blah, blah.

GK: Yeah, so what you would have done, you gave them a plan.

Paul: Yeah but I... I gave them like, a really stupid letter and I go like, if I was physically able to do this project, which you know I'm not, why set me the homework to do. But still this is how I would have done it.'

These pupils' views emphasise the importance of appropriate awareness and support from school staff to enable curriculum access and a sense of inclusion in school (a finding also noted by Lightfoot, *et al.*, 1999).

4.7.3 Significant Memories

In the later interviews I asked pupils about their significant memories of school life. Although these were inevitably selective and were representations of past events and how they were experienced by the pupils, what they chose to report was indicative of what had most salience for them. Many of the children mentioned their friendships and how these had developed and changed over their years at school, influenced by their own behaviour or experiences, such as changing tutor groups. David remembered being made a prefect in his last year of primary school. Ben in year 11 decided that he thought achieving independence and 'become more able to do things', perhaps the opposite of being disabled, particularly writing, were his main achievements at school.

A number of pupils mentioned Sports Days as memorable, with a variety of perceptions ranging from frustration through lack of participation to more positive views of having fun and enjoying the wheelchair race customarily held at the end of the day.

John recalled a bad fall and accidents he had experienced at school and at home (being very unsteady when he was on his feet) as significant events. Sam also recalled a time he fell out of his electrically operated wheelchair when he was out with a friend, and how a passer-by helped him back in off the road.

Sam's significant event was not in school, as such, but related to friendship and ordinary childhood pursuits, playing out with a friend: however it revealed his vulnerability and dependency as a wheelchair user, even in this context.

4.7.4 Receiving help from Learning Support Assistants

The young people talked to me about receiving help at the resourced secondary school. They mostly talked about receiving help from learning support assistants (LSAs) and from other pupils. There was very little mention of direct, individual support from teachers, who were seen as giving input to the whole class and helping other children, whilst the LSAs supported the disabled pupils. David described the process:

GK: 'Mmm, and does the LSA know when to help you?

David: Well usually they're there for the whole time and....And they, they find out what I gotta do....And then when they've done, when we find out what it is, we normally try and, if I don't get it, they try and make it easier for me and when I do grasp it, I, I get set, we set to work and then more or less get half of it done before the end of the lesson

GK: Right, right. What about the teachers then, if you're working with an LSA, how are the teachers with you?

David: They, I think they're, they are, they're explaining it, and then going around trying to help other people who are stuck....But the LSA spends time with me....And anybody else who needs it of course'

David described how he ignored other pupils whom he perceived as disruptive and concentrated on his work, supported by the LSA. The LSA helped make things easier and saved time, the LSA worked very closely with him and he was quite dependent on their support for understanding. The class teacher explained to the whole class and then helped

other pupils, whilst the LSA was there for the disabled pupils.. This inevitably reduced the disabled pupils' contact with the teachers and suggested that they got most of their support in lessons from teaching assistants. Research has shown that children who receive most support from teaching assistants at school make less progress than similar children with less teaching assistant support (Blatchford *et al.*, 2009). This is felt to be because the support from the teaching assistants reduces the overall amount of interaction pupils have with the teacher (this is nearly halved in the secondary school setting). Teaching assistants are less well qualified than teachers and their interactions with pupils are qualitatively different, being less effective and less educationally valuable compared with teacher-to-pupil interactions (Webster *et al.*, 2010).

Other disabled pupils rejected LSA help to some extent because they wanted to be seen as independent:

Aidan: 'I don't....I know this sounds cruel but I don't like them sitting next to me all the time.

GK: Right. How do you manage that?

Aidan: Because I think when people look at me they, they....what's the word....they see me always tied down to a LSA and I don't want, I don't want to rely on other people really because....obviously there's some things I can't do, but most of it I can'

Receiving help means being dependent and this can make the pupil vulnerable to bullying and 'interference' as Aidan's further comments illustrated:

Aidan: '...I'm basically alright in classes, the problem I have is, like, like, my bag. 'Cause obviously I've got like personal stuff in there. I let Emma get stuff out for me because ILike, the other day, someone got something out of my bag and like showed it everyone, and I'm like, dying, I'm like, 'Give it back here now'. It's just like, some people you can trust and others'll be like 'Oh, what's this?' There's this like snooping around and I'm like, 'Get lost'.'

Aidan was talking about his frustrations at being dependent on others for help getting things out of his bag, and how this could be abused by the other children – his need for privacy and control, his mortification and embarrassment when he lost control over his

privacy, leading to his anger and rejection of others. For Aidan, he tried to manage without LSAs and finally admitted to finding the LSA useful some of the time, but really he did not want to engage with them. Similarly to Aidan, John was keen to emphasise the bits he could do for himself, and when walking into the classroom he only needed 'an arm' not a person – just the physical support to carry out the activity himself. Neil described how the LSAs showed awareness of his need for help and when to leave him alone. They let him get on, and offered support if needed. Several of the pupils mentioned using red and green signal cards in the classroom, because they did not like to ask for help too publicly. Fraser found the help available at the school one of the things he liked about the school though he was quick to point out when he did not need it. Other disabled pupils such as Rory, appreciated LSA help but did not seem sure when it would be available, saying they sometimes got help and sometimes did not. David also talked about LSAs not always being available, because 'they're either away doing something else or exams', though I had the impression he would have liked them to be always around. Both David and Paul mentioned other pupils being jealous of the LSA support they received. The school had clearly given a lot of thought and training to their deployment of these support staff and although two of the disabled pupils mentioned particular LSAs in their school experience with whom they had had disagreements, on the whole the young people were generally very positive about their support and the pupil's role in requesting help when they needed it.

A further major disadvantage with receiving LSA support was noted by Paul, who pointed out that he could never get away with anything and had both the LSA and the teacher to deal with.

GK: And what's it like having that sort of help a lot?

Paul: It's good but on the other hand it's bad, because if I do... say there was a problem where you haven't done your homework... you've done your homework but you can't do it on the computer because you're printer's broken, you're going to get told off by the LSA for not handing in your homework, you get told off by the teacher for not handing in your home... and if they bump into Mrs S in the corridor, they're like, guess what Paul did in science today, you can't breathe without someone else breathing down your bloody neck.

GK: I see, yeah. So you get a lot more comments on what you do...

Paul: Yeah or reprimands, if you do something wrong, or it's like... or it's like, occasionally swore or something, it would be, oh you shouldn't

have done that Alison or you shouldn't have done that Emily um and carry on, but like I said, you shouldn't have done that Paul, you shouldn't have done that Paul, from about 15 different people.'

This issue of increased levels of adult surveillance for disabled pupils is one noted by other researchers (e.g. Watson *et al.*, 2000) and can result in these pupils having a distorted experience at school compared to the majority of pupils. It is important that the relationship between the pupils and the LSA is one of mutual respect and professionalism (see Skar and Tamm, 2001; Skar, 2003).

In summary, the necessary presence and utilisation of the LSAs to support the pupils' functional physical needs, often extending to any associated specific learning difficulties they had, raised a number of issues: it could inhibit access to the teacher for these pupils; most pupils wanted to be seen as self-reliant when they could be and only receive the minimum amount of help they required, when they needed it; the presence of the LSA was felt by some pupils to interfere with their relationships with their peer group; and a few pupils developed a dependency on LSA support which they missed when it was not available. In addition, it frequently resulted in abnormally high levels of adult surveillance of these pupils, which they frequently resented or tried to avoid.

4.7.5 Receiving help from other pupils

Most of the pupils talked about receiving help from their friends in class, either instead of or as well as LSAs. A number of pupils described how friends helped out when there was no other help available. David also talked about receiving help from other pupils though not in the spontaneous way other disabled youngsters described, rather as a planned activity, when they worked in pairs, with supervision from the LSA. David gave a very literal, limited description of the process, without reflection on its interpersonal and social impact upon him.

The pupils varied in their opinion regarding whether receiving help from LSAs affected their relationships with other pupils, Ben did not see receiving help from LSAs as affecting his friendships with other pupils and he saw the teachers and other pupils as helping him when he asked for it, very much seeing himself as the active agent. However Neil did feel that having LSA support affected his experience in class:

Neil: ‘Um [7 *seconds*] I think like when you’re trying to make friends or whatever and you’re trying to talk to them or whatever and if you’ve got somebody who’s just sitting beside you all the time it’s quite hard to... for them to kind of talk to you because they feel like there’s somebody there. And sometimes like my friends get stuff out of my bag for me and then there’s somebody there, so they sometimes feel a bit pushed aside.... Kind of they’re used to doing it and then somebody else starts doing it....But I think most of the time it doesn’t bother them or anything’.

In this school the presence of LSAs in the classroom was common place and on the whole they did move around the room, helping any pupil who needed support. It seemed to be more problematic if they sat beside the disabled pupil and effectively became a barrier to their interactions with the other pupils.

4.7.6 Achieving independence

Achieving independence was very important to many of the disabled pupils. As described above, Aidan was very keen to achieve and maintain his independence at school, and perceived reliance on others, whom he may not trust, was seen as very threatening to his self-identity. This extended to his home life too and his interviews in particularly in year 9 and again in year 11 reflected these aspirations:

Aidan: ‘I don’t want to rely on other people really because....obviously there’s some things I can’t do, but most of it I can, like...and....like....simple stuff like going shopping with a few people....’cause our next car will be one I can fit this in [*points to motorised wheelchair*]. I’ll be able to do the food shopping like, we can all split off in different aisles and then meet back somewhere. I know this sounds bizarre and silly, but I would love to do that.’

Transport was a major issue here and had been mentioned by other pupils.

In contrast to Aidan’s aspirations, Rory seemed not to have considered this, but clearly led a very home based and limited life style. This may have been influenced by having a disabled brother, in addition to possible additional learning needs (less articulate, memory difficulties, etc.) and also material barriers, as they lived with a single parent mother with

mental health issues. I talked to him about issues raised in the interviews with other disabled pupils:

GK: 'Independence is very important to them

Rory: What's that? [*stretches arms*]

GK: Sort of getting out after school and

Rory: No

GK: Going out with friends

Rory: No

GK: No what?

Rory: I don't

GK: How do you feel about that?

Rory: I feel great

GK: You don't mind?

Rory: Yep I don't mind

GK: So what sort of things do you do at home?

Rory: Play, watch TV, play PlayStation or X-Box....mostly watch TV'

My discussions with Ben, particularly in year 11, and several of the other young people revealed a similar home based life style.

For some pupils, like Sam, who had muscular dystrophy, their degree of physical impairment meant that there was very little they could do on their own, though this was clearly very important to them, and they were resigned to being dependent on support.

I asked Paul how he felt about being independent, but he did not think it was possible, given his impairment:

Paul: 'Well I'd like to be but then I wouldn't like to be because I know there'd be no one there to help me sort of thing.... Um... um I hate depending on LSAs to do everything but I know for some things it can't be avoided.'

However, being able to direct the help he received helped Paul and Sam feeling in control and maximised their agency.

Neil accepted that he might need help at times, but did not like asking for it unless forced and always tried to do it himself first:

Neil: 'Uh I think I'm just stubborn and would always... I'd always rather do things by myself but sometimes I can't or...

GK: Do you ever ask other people to help?

Neil: I try first and if I can't do it or I'm going to look like a right idiot I get other people, I kind of ask other people to help me do something.

GK: Do people ask you if you need help?

Neil: Yeah most of the time they do but I kind of say, oh wait a minute, I'll try and do it myself and if I can't do it I'll get back to you.'

Other pupils referred to wanting to be independent too and their family supported them with this:

Fraser: 'Sometimes I do like my... just to let me get on with it, sometimes I do literally just say, can you just let me get on with it.

GK:so that's important to you, yeah. And do you get independence out of school as well do you think?

Fraser: Yeah.

GK: In what ways?

Fraser: I suppose I can do what I want but you know,..... Obviously my sisters and that are always looking out for me....but otherwise they're... they're just like, well if you want to you know what you can and can't do.'

For these youngsters, from an affirmative and social model perspective, they need to be able to deal with the predicament of their impairment and then to have access to a broad and balanced curriculum appropriate for their needs alongside their peers in an environment where all differences are accepted and celebrated, rather than being exclusionary and separating.

Chapter 5: DISCUSSION

5.1 Research Question 1

My first research question considered **how my approach to this research could promote the engagement of the participants and ensure their views were heard** and I have addressed the nature and design of such an approach in Chapter 2 (Methodology and Methods) and Chapter 3 (Ethical Issues). In my research practice I placed the engagement and informed involvement of the disabled young people as of paramount importance and careful consideration was given throughout the lifetime of the research to promoting this. Semi-structured individual interviews were used with these 13 to 15 year olds, giving them as much time as they required to respond, and these were recorded, to allow for careful transcribing where there was much repetition or unclear pronunciation. Other researchers consulting with disabled children have used different methods, depending on a variety of factors, such as the age (e.g. Clark, 2004) or the degree of communicative impairment (e.g. Morris, 2003) of the child; however in the present study the participants were able to communicate effectively verbally and would have been restricted in their ability to access alternative methods such as drawing, writing or operating equipment. On reflection, the method I chose to use was very researcher led, albeit a disabled researcher, and for future research of this kind it would be important to consider how the disabled children themselves might take on the role of researcher with support, to strengthen their voice and to embed their participation and involvement in their education (Prilleltensky, 2010). In addition, the use of a focus group to check out some of the issues raised by the pupils, to see if they reflect common experience might be considered. Where multiple interviews took place (with three of the pupils), these were felt to have added extra depth and a longitudinal aspect to the study, and an extension of this approach, might be considered. This would give the pupils not only ‘extended’ engagement with the research, but also provide opportunities for reflection and developing their own voice and how it is represented by the research.

5.2 Research Question 2

In **describing their experience of being a disabled pupil** in the school the children raised a variety of issues of significance to them. I have attempted to maximise their voice in this research and have reported at length their comments and explanations in Chapter 4 (Findings and Interpretation). My interpretation of what they said to me about being a disabled pupil in the school led to the identification of a number of core themes and

categories within these (see Figure 4.1, p. 73). I would like to analyse these themes here, in relation to two of the research questions posed on page 49 in Chapter 1.

5.3 Research Question 3: How do these pupils perceive themselves and how do they express this in their self-descriptions and reflections on their experience of school?

5.3.1 Impairment and not disability

My conversation with each pupil concerned asking them to tell me about themselves and their experience in school. Specifically I set the context by saying I was wishing to talk about their experience as a *disabled* pupil in the school. The children talked about their impairments and the functional limitations they experienced because of these, and often, about how these were overcome or circumvented in various ways. They talked about restrictions of activity resulting from living with their impairments ('impairment effects', Thomas, 1999) as well as restrictions caused by social (e.g. distance from school) and material (e.g. lack of adapted transport in the family) barriers. This contrasts with Connors and Stalker (2007) who suggest the children in their study only mentioned impairment effects but is similar to Priestley *et al.* (1999) where children identified the social barriers they experienced. However, the majority of pupils did not take on board the descriptor of 'disabled' for themselves although they accepted that this was terminology used by adults and society around them and indeed, a term they might use themselves in talking about others (David uses the term when watching TV with his mother). This has been noted by other recent researchers, who have sought the perspectives of disabled people (Watson, 2002; Shakespeare, 2006). For these pupils their physical impairment presented them with a 'predicament' (Shakespeare, 2006) which they needed to deal with, through the organisation of their day, through having an accessible environment and the equipment and aids they need, through appropriate support and differentiation from the adults and their peers in school. Yet they were aware that they came to this particular school as 'PD resourced pupils' – a categorisation which had been placed upon them by the local authority, following the SEN procedures set down by central government legislation. There was general resistance to being perceived as 'disabled' and this was generally seen as a negative term indicating that they were not able to do anything. One or two of the pupils mentioned some positive connotations relating to perceived 'privileges' in school such as getting out of lessons early or receiving extra support (affirmative model). These children saw that their disability could be a resource. However, most of the participants avoided the identity because of its negative connotations. As disabled comedian Adam Hills (2005)

comments “Simply ask them whether or not they consider themselves to be disabled. If they think they are, they’re probably not”. As Shakespeare and Watson (2001) note:

“Many disabled people do not want to see themselves as disabled, either in terms of the medical model or social model. They downplay the significance of their impairments, and seek access to a mainstream identity. They do not have a political identity, because they do not see themselves as part of the disability movement either.” (p. 20)

Watson (2002) points out that whether the shared identity claimed by the Disabled People’s Movement, who have politically campaigned for civil rights for disabled people, exists amongst Britain’s 10 million disabled people has not been explored and his research set out to do this. Only 3 of his 28 adult participants incorporated disability within their identity, rejecting their impairment as a central characteristic of their self-descriptions. The vast majority did not see impairment as important to their sense of identity or self – “their accounts suggest that their physicality did not produce a difference between themselves and nondisabled people, challenging the universal ‘biological’ self” (p. 514).

Watson’s research suggests that, in many cases, his participants were brought up as children to perceive themselves as disabled and that this perception was often reinforced by the social settings they were placed in – e.g. special schools, resourced provision, children’s homes. However it also presents evidence that as they get older they choose to reject this identity in favour of seeking a more normalised identity, where their impairment is recognised, but is not a determining factor in their self-identity. They recognise the social oppression, injustices and prejudices directed at disabled people, therefore they do not choose to be identified as such (Watson, 2002).

Skar (2003) also found that their disability had little significance for how adolescents saw themselves and how they identified with their peers. They saw themselves as just like all teenagers and named personal attributes such as kind, happy, determined and careful. They also mentioned what they were good at. However, when they reported how they thought others saw them, they mentioned their disability, feeling they were often judged on the basis of this, rather than themselves as a person. They were unwilling to talk about their disability with others, particularly their peers, because of this, for fear of negative consequences.

The views presented by the young people in the present study certainly concur with these interpretations. These pupils saw themselves as teenagers first with physical impairments which they may wish to acknowledge in some settings, but not need to in others. Ben mentions difficulties with using pins in year 9 for which he receives LSA support; by year 11 this is no longer an issue because he does not do sewing any more. Paul sees himself as doing ‘everything around a chair instead of on my legs, that’s all’. Disabled people have multiple identities which vary across time and settings (Shakespeare, 2006) and as they establish more control over their lives, having an impairment is of less significance.

Watson *et al.* (2000) also found that the children in their study were unwilling to identify as disabled. In a subsequent paper they criticise the social model as not “reconciling the dimensions of gender, race and sexuality with or alongside disability” and suggest that there is a tendency for this model to over-simplify identity issues:

“Most people are simultaneously situated in a range of subject positions. To assume that disability will always be the key to their identity is to recapitulate the error made by those from the medical model perspective who define people by their impairment. Any individual disabled person may strategically identify, at different times, as a person with a particular impairment, as a disabled person, or by their particular gender, ethnicity, sexuality, occupation, religion, or football team. Identity cannot be straightforwardly read off any more, it is, within limit, a matter of choice” (Shakespeare and Watson, 2001, p. 21).

Several young people mentioned pain, illness or operations experienced as a result of their impairments (John, Neil, Rory, Sam) though were not always prepared to equate the two (Neil does not see urinary tract infections as part of his disability). Social model explanations of disability, whilst useful in fighting for social change, are not entirely adequate, since a number of the pupils do refer to limitations set by their impairments, which would exist if all external physical and attitudinal barriers were removed. The interactional model perhaps offers a way of incorporating more of the complexity of factors in each individual’s circumstances to promote a holistic understanding (Shakespeare, 2006).

Some researchers have suggested that disabled young people can lack a positive language with which to discuss difference and disability and tend to minimize or deny their differences (Connors and Stalker, 2007). The pupils in the present study mostly talked about disability in negative terms and resisted its application to themselves, but given societal perceptions of disability this is perhaps not surprising (Watson, 2002). More affirmative awareness of difference including disability might be encouraged in schools, through information and discussion, role modeling and contact with disabled adults to change the negative connotations of the descriptors in use.

5.3.2 Difference

An issue which was not anticipated in my research questions, but which was significant to these young people, was that of how they felt they were perceived by other non-disabled people in school. Being perceived as different in the school, particularly by the non-disabled pupils, was raised explicitly by two of the pupils interviewed, and was a recurrent theme more implicitly for others. None of the pupils particularly wanted to be seen as different, two felt they were and were seen by other non-disabled pupils as part of the group of disabled pupils associated with the resourced provision. They felt this contrasted sharply with their primary school where they had been more accepted. Another pupil, felt more accepted at the resourced secondary provision where there was a larger group of other disabled pupils, having been permanently excluded from his primary school. These pupils strongly resisted being made to feel different and argued vociferously for the sameness of the inner person, in spite of the visible physical differences. Other researchers have also noted the importance of the experience of difference in the experience of disability (Watson *et al.*, 2000; Connors and Stalker, 2007; MacArthur *et al.*, 2007). This ‘sense of being made to feel different’ may have something to do with their impairment, particularly its visible stigmatising effect (Goffman, 1963), but there are other contextual elements mediating this for the children, e.g. their relationships with others, particularly peers, and the cultural and structural aspects of the school setting. The pupils were frequently positive, active agents who were refusing to see impairment and disability as a defining feature of their identities and in this way were ‘using their agency’ to resist these disabling, oppressive experiences. Paul referred to being stared at by other pupils, and inappropriately questioned about his toileting – he had become fair game for such approaches which would be considered unacceptable made to other pupils with less visible differences, suggesting a power imbalance and unequal status (Foucault, 1967). He had a verbal retort ready to re-establish his agency. These pupils were fighting back, being active agents and resisting discrimination, bullying and being singled out as different. In this way

the pupils can be seen to be standing up for their rights and aspiring to overcome their ‘predicament’ to achieve typical teenage goals.

The pupils wanted their impairments to be accepted as part of them without being an issue, and they were seeking acceptance without being made to feel inadequate. For some, differences which had been accepted in primary school were no longer unquestioned and the pupil was encouraged to conform to certain expectations in the secondary school. Neil felt he was very independent in primary school and was able to get out of his chair and move around on the floor. However this was discouraged when he moved to the resourced secondary school, by the occupational therapist who said it was not gentlemanly to do so, since this time Neil had stayed in the wheelchair at school. Neil’s active agency was compromised by being told it was no longer appropriate to use a means of mobility he had been comfortable using at primary school and was able to use in other settings, such as at home or at a disabled youth group. Neil had become unhappy at the mainstream school and was seeking transfer to a special school where he said, ‘I don’t feel different when I’m up there; I’m kind of the same as everybody else. Here I kind of always feel different and you’re never good enough here and up there I didn’t feel like that when I was there.’ Not being accepted for what he was, including his chosen mode of mobility, had reinforced this feeling of not belonging in the resourced secondary school provision.

5.4 Research Question 4: What issues do these views raise for educationalists, practitioners and policy makers working towards inclusion?

5.4.1 Transition to secondary school

Transition to secondary school raises issues of importance to all children (Galton *et al.*, 1999; McGee *et al.*, 2004; Evangelou *et al.*, 2008) and the pupils in the present study raised a number of additional issues relevant to their experience of transitioning to a resourced secondary school provision, including feeling forced away from their local communities; losing friends; increased distance from home; encountering change and difference relevant to their ‘predicaments’.

Article 3 of the United Nations Convention on the Rights of the Child refers to the best interests of the child as a primary consideration in all work with children, but often it is adult need and interests that drive priorities, leaving children feeling excluded and marginalised as a result (Morgan *et al.*, 2002; Ruddock, 2006). The disabled children in

this research wanted to belong to the group of all children in their school, where diversity was accepted and responded to in a positive way. Yet it is more convenient to group children together for economy, to access therapies, to make one school amongst many accessible, and not all, to create a specialist teaching force (HCC, 1990; Cuckle and Wilson, 2002; see section 1.7) when in fact all children would benefit from differentiation and targeted support to meet their individual needs. In this research nearly all the pupils would have preferred to transfer to secondary schools within their neighbourhoods, alongside their peers. They did not want to be seen as different, as members of the ‘resourced provision’ rather than the school. They wanted their impairment not to be the determining factor in their identity as seen by others.

In this school all the disabled pupils belonged to and registered with a tutor group and received all their lessons in the ordinary classes (unlike Cuckle and Wilson (2002), where the children registered in the bases). There was a base in the school with accessible toilet facilities, a physiotherapy room and a learning support centre which was used by any of the pupils in the school when they were determined to need additional learning support on a withdrawal basis. This was considered to be an inclusive arrangement by the school which aimed not to differentiate its support to pupils on the basis of whether or not they were registered through the resourced provision. However, it was apparent, in my conversations with the disabled pupils, that they understood themselves to be ‘resourced PD pupils’, where ‘PD’ stands for physically disabled (see Section 4.4). Although the school and LA had gone some way within social model thinking in their attempts to remove the environmental and attitudinal barriers to include these pupils in mainstream settings, it was clear that drivers within the SEN system and the use of clearly labelled ‘resourced PD provision’ reflected medical model thinking which involved the explicit identification and categorisation of the individual pupil in terms of their disability and subsequent needs. This potentially stigmatises the child and sets them apart as different in a fundamental way (Goffman, 1963). If considered in the light of recent developments in thinking about models of disability, discussed in Section 1.4, it is apparent that although attempts had been made to remove physical barriers in this school, the construction of the environment and the systemic operations within the school were still disabling these pupils in terms of social perceptions (social relational model, Thomas, 1999; interactional model, Shakespeare, 2006).

Policy makers and practitioners need to be aware of these issues when reviewing and developing provision in the future and consider how policy and practice can better support individual needs without stigmatisation.

5.4.2 Friendship

Friendship was a significant factor for all the pupils in my study, similar to findings reported by Whittaker *et al.* (1998), (see section 1.13.3 above) and was mentioned in a number of contexts, particularly the loss of friends, when the pupils moved to the resourced provision; the lack of opportunity to see friends out of school because of the distance travelled to attend school and a lack of accessible transport or sufficient independence to visit friends or meet up with them in town or at leisure centres. Some of the pupils were very bothered by this, others seem resigned, whilst others seemed more family and adult focused.

By early adolescence friendship circles can be wide (Cotterell, 2007) but these networks can be easily disrupted by changes in circumstances, such as moving house, or moving school, changes which can be daunting for adolescents and feelings of loneliness and disconnection can occur (Clark, 2009). Other studies where the views of disabled children have been sought have also noted few experiences of peer contact outside school hours, e.g. Skar (2003), though the reason given was that the adolescents felt that they had been excluded from the peer group at an early age because they were unable to participate on equal terms in different physical environments and so did not establish deep bonds of friendship. This contrasted with my research, where most of the children had lots of friends at primary school and the need to transfer to the resourced secondary school which was not the same school chosen by their peers and was at some distance from their home, in addition to a lack of transport and finance and over-protectiveness of parents, were the main reasons given. In her study of adolescents' (10 – 14 years) use of social networking sites on the internet, Clark (2009) found that this can play a role in providing online emotional support to friends through periods of change. Internet access may provide similar support for disabled adolescents, though material barriers would need to be overcome to enable them to access the equipment and technical support they need to use these sites. There was little mention of this in the present study, the indications were that these adolescents did not have the material resources at home or the skills, knowledge or independent ability to operate IT equipment without support. Research into the use of new computer technologies to support learning suggest that it is relatively affluent youngsters, with high specification computers and broadband access at home that are mostly likely to

use these facilities (Sheehy and Ferguson, 2008). It has been argued that access to the internet is a basic right (Paveley, 2002).

“There is evidence that information poverty will follow existing patterns of economic inequality in society and that those unable to use and access new technologies will be excluded from key economic and social activities (Webster, 1995; Facer and Furlong, 2001). In line with this view, disabled people have reported that their greatest barriers to internet access are financial (Seale, 2001)” (Sheehy and Ferguson, 2008, p. 171).

It is apparent that the disabled pupils in this research might benefit from the use of technology in social networking, given the difficulties imposed by living great distances from the community of peers they meet in school and with independent transport. There were a number of possible interacting factors contributing to their failure to do this – the pupil’s family circumstances often mitigated against this being pursued, e.g. separated parents, where the young person spends some time at each home; poverty, often tied in with there being other disabled members in the family and a single parent; the extent of their physical impairments making unsupported computer access very difficult; competition for the technological resource in the family; a passive attitude or lack of self-confidence not leading to fully utilising what equipment they already have (e.g. Aidan and his mobile phone – not telling his mum where he is). This would be a useful area for future research and consideration for social policy making – to help these youngsters to take an active social role, government agencies such as Children’s Services may need to think beyond the institution, consider the child holistically and enable them to access a wider social network (children value online friendships highly, see Clark, 2009) through providing them with the support they need to set up technological systems outside school to enable them to be active participants in society.

5.4.3 Bullying

In this research bullying was a significant issue raised by some of the disabled pupils and this occurred with both non-disabled and disabled pupils. Bullying is an issue of central concern within our education system at the present time and has been particularly noted in government policy agendas, including specific concern for ‘pupils with special educational needs and disability’ (see DCSF, 2008, for guidance to schools regarding understanding, preventing and responding to such bullying). For some of the disabled pupils in this study

(e.g. Paul, John, Aidan) bullying was seen as one aspect of being perceived as different by others, or as lesser human beings. There were clear indications from these pupils of their need for such issues to be tackled by the school, which they were to some extent, but they were not fully resolved and they reoccurred. A number of the pupils described how they resisted such peer abuse, sometimes equally inappropriately (as was also found in MacArthur *et al.*, 2007). These disabled pupils were clearly able to articulate their perceptions and feelings and fuller involvement of them as participants within the school's strategic plan to develop an inclusive school, accepting of diversity, might be considered (affirmative model). Some researchers have begun to explore friendship as a context for the development of adaptive behaviour (Berndt, 2002). There has been extensive research on the role of acceptance and friendship in promoting a sense of school belonging in adolescence (Hamm and Faircloth, 2005). School belonging refers to the pupils' perceptions that they are liked, respected and valued by others and have a 'sense of community' at school (Osterman, 2000). The context described by these pupils, suggested that there is some way to go to achieve this for these disabled pupils.

5.4.4 The importance of listening to disabled children

Thomas (1998), when discussing the use and interpretation of the retrospective narratives of disabled women, comments:

“We have access to ‘truths’ about living as children with disability as constructed by active subjects and this draws our attention to those childhood experiences which have lasting meaning and effect. This can be an important guide to policy and practice in the disability field”

p. 87

This applies equally to the conversations in the present study with the disabled pupils in year 9 and year 11 attending the resourced secondary provision. These disabled pupils had a lot to say about their experience of school (see section 4.7). Generally the pupils were positive about school (with one exception) though they had certain specific criticisms which warranted being heard by school staff and treated as a valid contribution to their individual education plan (Special Educational Needs Code of Practice, 2001).

The amount of time the disabled pupils spent with adults and under adult surveillance was very noticeable (Ben and his use of adult phrases, his description of friendships as adopting

the adult caring role; Aidan, in his rejection of LSA support which led to his exclusion from school in his primary years and his bare tolerance of it in the secondary school; Paul and his mention of always being reported for everything he did wrong, many times). Other researchers have described this as a key finding when seeking pupils' views on their experience at school (Watson *et al.*, 2000; Skar and Tamm, 2001; Skar, 2003). Some of the pupils actively resisted this, as did Aidan and Neil in this research. The pupils were generally happy with the deployment of learning support assistants (LSA) in the resourced secondary school – they seemed to indicate that the balance was right between the LSA being available and standing back until help was requested, though the pupils indicated that they would find their close presence restrictive in terms of social interaction with their peer group, and indeed, teachers, and their full inclusion in the classroom.

Comments from some of the pupils suggested that pupils who cannot take part in lessons want teachers to make constructive alternative arrangements, such as using the time for physiotherapy or catching up on another subject, and individualising this depends on the teacher listening to the views of the pupil (Lightfoot, *et al.*, 1999; Skar and Tamm, 2001).

An experience discussed by one of the disabled pupil's which he deemed that the school had imposed upon him without appropriate consultation was that of Aidan's experience of being moved from his tutor group to another, at the discretion of the school, in year 9. He attributed this move to his behaviour difficulties and the negative impact of his presence in this tutor group. This raises questions about the effectiveness of such strategies and what impact they have upon the pupil(s) involved. In his second interview in year 11 Aidan reported that he was distressed and confused by this at the time, though he later admitted that it turned out for the better and enabled him to remain in school rather than being excluded. There is extensive research demonstrating the impact of school factors upon pupil progress, including classroom management and school organisation (e.g. Rutter, 1983; Carrington and Elkins, 2002; Thuen and Bru, 2009). Recent research looking at managed moves between schools to avoid permanent exclusion (Vincent *et al.*, 2007) has found that it is how the move proceeds and develops that ultimately makes the difference for the pupil, rather than the move itself. In this work the concepts of tailored support, care and commitment emerged as strong themes in the re-engagement of the vulnerable pupils. The importance of full consultation and involvement of the young person involved is underlined. There is an absence of research into the effectiveness of moving tutor groups specifically within school and its psychological, emotional and behavioural impact on the pupil involved and his peer group. This is an area which warrants further research,

including that of the need to seek the views and comments directly from the pupil involved.

Talking to the pupils about these issues and listening to them, with a genuine intention to respond to their requests or ideas, and at the very least, to actively problem solve together, would lead to a greater sense of belonging and acceptance. Pupils can be active agents for change in the classroom as well though their comments are often ignored (MacArthur *et al.*, 2007), asking for their feedback and involvement in active problem solving may well be fundamental to finding a solution, e.g. Neil's comments re missing notification of school trips because of leaving for the bus early; comments from pupils about teachers making constructive alternative arrangements when they cannot take part in an activity, such as using the time for physiotherapy or catching up on another subject. Individualising this depends on the teacher listening to the views of the pupil (Lightfoot, *et al.*, 1999; Skar and Tamm, 2001) *and* consulting them about solutions. This would be a good area for further research.

5.4.5 Towards an affirmative model

Some of the pupils struggled to find the vocabulary or linguistic devices they needed to discuss the issues they experienced connected with the disabling outcomes of their impairments (Rory, Fraser). Connors and Stalker (2007) have raised the issue that this might be a factor for some children, particularly younger ones (the children in their study ranged from 7 to 15 years) because they did not have a language with which to discuss difference, with a lack of positive role models of disabled people or access to information and ideas about models of disability. To promote the empowerment and affirmation of disabled people educational practitioners and policy makers might consider the inclusion of these in the curriculum for all pupils. Leicester (1999) calls for an 'enabling education' where all children would receive a disability aware education and so would not acquire prejudice through the schooling process. In line with the affirmative model of disability, the social model perspective on disability *and* the affirmation of the value of difference must become shared by mainstream teachers and pupils. In addition disability awareness should permeate adult education and inform the mass media and other informal learning in our culture.

5.5 Conclusion

During the lifetime of my research into seeking the views and perspectives of young disabled people there has been a significant momentum for change and a recognition that

these young people's views should be genuinely sought, with a move away from paying only lip service to this, to an exploration of the means by which it can be most successfully achieved (Section 29A of the Education Act, 2002, CRAE, 2008; Hear by Right; Participation Works).

Researchers working with other marginalised groups (e.g. young people with severe learning difficulties, children from travelling communities) have emphasised the importance of not only listening to what pupils say, but also reflecting upon what is heard and taking it into account:

“The voices of these young people challenge us as educators to reconsider the ways in which we engage with the discourse of inclusion. This will only be achieved if, in addition to listening, we are prepared to act and to confront the obstacles which still stand in the way of creating an education system which is truly committed to providing an inclusive ideal” (Rose and Shelvin, 2004, p. 160)

There are a number of challenges to this process, including those who feel that giving children more of a voice may undermine teacher authority and substantially change the power relationships in schools (Flutter, 2007). Ensuring all pupils have the opportunity to express their views and have them heard, given that pupils' contributions can vary widely, is another challenge (May, 2005). How the implications of these views are interpreted and used to inform decision making is a further challenge, incorporating the 'worm's eye' view with the 'bird's eye' view to develop an understanding of what works (Wood, 2010).

The views of the pupils in this study were by no means unanimous and frequently there were different opinions based on a complexity of factors including the impairment of the child, the support and material circumstances at home and the views of their parents, the children's previous school experience, and a range of other factors. Most of the studies where pupil voice has been listened to have concluded that there is no universal concept of 'a disabled child' and situational and contextual as well as individual factors will all play a part. However, listening to children's voices will lead to a more 'nuanced' understanding of their lives (Watson *et al.*, 2000):

“Our data suggests that where children encounter disablist practices in schools, they should be encouraged to put forward their own solutions to their problems. If given space, they are capable of empowering themselves where they encounter teachers and other adult helpers, provided these adults reflexively question their own practices.”

(Watson *et al.*, 2000, p. 16)

Disabled children are not a homogeneous group however, and have a range of perspectives on their school life, so teachers will need to be prepared to listen and respond to a wide range of voices and opinions and adjust the school setting accordingly. Adults need to take account of every child’s individual needs – teachers need to be reflexive in their practice to avoid discrimination and support all children’s rights (Watson *et al.*, 2000; MacArthur *et al.*, 2007). They also need professional development opportunities both in initial training and ongoing within their institutions.

Chapter 6: CRITICAL REFLECTIONS AND IMPLICATIONS FOR FUTURE RESEARCH

6.1 Summary

In Chapter 1 the need for further research seeking the views of disabled children and young people on their experiences at school was established. The following research questions were proposed and have been addressed in the present study:

1. How can my approach to this research promote the engagement of the participants and ensure their views are heard?

Chapters 2 and 3 describe the methodological and ethical approaches used in this study to facilitate the involvement of these disabled young people

2. What are the children's experiences of being a disabled pupil in the school?

Chapter 4 presented my findings and interpretations following my lengthy conversations with 10 disabled pupils who attended a resourced mainstream secondary school. I have made great efforts in presenting the findings to report back the views as they were expressed to me by the pupils themselves.

3. How do these pupils perceive themselves and how do they express this in their self-descriptions and reflections on their experiences in school?

Chapter 5, section 5.3 addresses this question, based on the findings in Chapter 4. An additional aspect of how the pupils felt they were perceived by others emerged from the analysis of their comments and is also discussed.

4. What issues do these views raise for educationalists, practitioners and policy makers working towards inclusion?

Chapter 5, section 5.4 provides a summary of the issues raised in the themes identified in this research which have relevance to those responsible for these disabled pupils' inclusive education.

6.2 Critical reflections and implications for future research

The present study makes a unique contribution to qualitative research on the experiences of disabled young people in mainstream schools by focusing on the expressed views of their school experience of year 9 and year 11 pupils in a mainstream secondary resourced provision. Other studies (e.g. Priestley *et al.*, 1999; Watson *et al.*, 2000; Connors and

Stalker, 2007) also report using semi-structured interviews, but frequently have a wider age range, variety of impairments, range of types of school but not resourced schools and the involvement of other adults such as parents and teachers. In the present study the pupils were active participants, in that the interviews were relaxed and taken at their pace, with active listening skills practiced by the disabled interviewer to promote their participation and hear what they had to say. Some of these pupils were interviewed on a second occasion, which provided an opportunity to explore further with them the general issues raised by both themselves and their peers and also added further depth by introducing a passage of time factor to their reflections on their experience. Throughout this process the involvement of a disabled researcher contributed further to the uniqueness of this study and encouraged the participants to want to share their views – in their own words ‘because I feel I can discuss a lot more.....because they could relate to it because they’re in the same boat’ (Paul). This research sought the pupils’ full engagement in individual in-depth, lengthy but relaxed semi-structured interviews, using open-ended non-directive questions, without the presence of other people and taking care to capture the detail of what each participant said, through the use of video and meticulous transcribing. Grounded theory methodology was used to analyse the transcripts allowing the messages conveyed by the study to be grounded in the data.

In addition, to being a disabled researcher, although an adult, I was familiar to about half of the participants as a visiting support professional and had met with all of them to ensure that they were able to make an informed decision to become involved. I attempted to promote “fruitful interaction by re-negotiating the power relations between adult and child” (Davis, 1998, p. 329), using active listening skills and adopting a non-authoritarian/non-teacher role which was acceptable to the children.

“Empowerment is associated with allowing children to choose to become active participants in the research process, employing tools which offer children the maximum opportunity to put forward their views and reducing the social distance and re-negotiating the power relations between researcher and child” (Davis, 1998, p. 329).

As an ‘outsider’ myself to the school (Hellawell, 2006), I was not in a position to facilitate research which allowed the children to become active researchers themselves (Hart, 1997), but rather aimed to achieve consulting and sharing my interpretations with the children to make sure their voice was heard. The use of semi-structured interviews was

very productive with the participants in my study who would have difficulties with other ‘child-friendly’ techniques involving drawing or writing because of their physical impairments, and was a sensitive way to explore their meanings and understandings (Stroh, 2000). Where second interviews were carried out, although occurring over two years later and having even less structure, being a revisiting of themes identified in the first interview, these proved to be lengthy and informative. The participants were two years older (then in Year 11) which may have been an influencing factor, but this does suggest that a longitudinal study, using multiple interviews would be an appropriate methodology for future research of this kind.

The themes arising from the analysis in this study concur to a large extent with those found by other researchers seeking to portray the views of disabled children (Priestley *et al.*, 1999; Watson *et al.*, 2000; Skar and Tamm, 2001; Skar, 2003; Connors and Stalker, 2007; MacArthur *et al.*, 2007). These previous studies also report using semi-structured interviews, but frequently have a wider age range, variety of impairments, range of types of school, and are designed differently in terms of where the interviews were held and how they were structured, including the involvement of other adults such as parents or teachers. In the present study the interviews proceeded well and the pupils were positively and enthusiastically engaged. They all welcomed having a disabled researcher: ‘Quite good because they can understand, because otherwise if I’m just like talking to I suppose like Miss D or someone it’s just like her hearing me saying it and her not actually knowing what it’s like’ (Fraser). Having a disabled researcher was valued by the participants - the need for future disability research to employ disabled researchers to promote a more emancipatory agenda has been noted but is frequently inhibited by extra costs both material and in terms of time, and indeed social barriers such as physical and attitudinal access (Oliver and Barnes, 1997). My own research experience was facilitated by the fact that the resourced school in the study had been fully adapted by the LA and this included the heightened awareness of the head teacher and staff who shared my belief in the importance of the aims of the research. In contrast, my attempts to interview disabled pupils in non-resourced secondary schools was time consuming and eventually unsuccessful, for a variety of reasons, one of which may have been that the ‘gatekeepers’ in these settings did not share my beliefs regarding the importance of my research (see section 3.3). However, future research might also aim to involve the disabled pupils more in the development of the research agenda and this could most effectively be carried out as a form of action research facilitated by a member of staff at the school (Kellett, 2005; Hellawell, 2006), perhaps disabled themselves.

During the process of the interviews my first statement and question: “I would like to talk about the experience of being a *disabled* pupil in this school” and question “Tell me about your disability” may have set up an expectation of, at best, a social model which suggested that the pupils were disadvantaged in some way by being ‘disabled’ in the school setting, and at worst, medical model thinking. I wanted to explore the language used in the school and by the pupils by asking them directly near the start of the interview. By introducing this term early on I may have restricted exploration of these issues by the constraints of my own assumptions and agendas. This issue is mentioned by Connors and Stalker (2007), in their study of 26 children and young people from a range of age groups, with a variety of impairments, attending different types of school, who describe their approach:

“We did not include direct questions about impairment in the children’s interview schedules, nor did we think it appropriate to ask the children, in so many words, how they ‘understood disability’. Rather, we preferred to wait and see what they had to say on these topics while telling us about their daily lives generally and in response to specific questions” (p. 22-23).

In the first interview in 2004 I introduced exploration of the term ‘disability’ near the end of the interview, subsequently I tackled it at the beginning. However, not to address it directly, as in Connors and Stalker (2007) above, did not seem to be an option, given that both myself and the pupils clearly had physical impairments and it was part of the agenda of the research study. This raised a need to explore the language used by the interviewees in relation to their disability, but to recognise that this might have been constrained by the language I introduced in the interview, in setting the research agenda and through the prompts I used. Priestley *et al.* (1999) also asked the children in their study about disability directly, and found a similar range of responses to mine, and the conclusions of Connors and Stalker (2007), who did not ask directly, are also very similar.

A strength of the present study is that it attempts to give an insider perspective (Hammersley and Atkinson, 1995), by reflecting the views of the disabled pupils in the resourced provision. Although only a small number of pupils were interviewed, mostly from one year group (year 9) a ‘rich description’ emerged of their school experience (Denzin and Lincoln, 2000, p. 10). Only three of these pupils received follow up interviews and there was a considerable time gap between these interviews, however the depth they added to the researcher’s understandings was significant, in that different perspectives

emerged, through the pupils reflecting back on issues they had raised in year 9 and the experiences they had had since that time. Further studies with longitudinal designs would be useful, if possible across different settings, to build a more comprehensive awareness, understanding and knowledge about the experiences of young disabled people as they progress through school and move into adulthood.

The children who took part in this study chose to do so, following my description of the research agenda and the findings reported are my interpretations of their views. Some children chose not to participate, probably for a variety of reasons, one of which may have been that the research was about being a disabled pupil, an agenda with which they did not want to identify. Future research might consider different ways of engaging more disabled children in research agendas of relevance and significance to them, including developing the pupils themselves as researchers, as mentioned above (Kellett, 2005).

The process of transcribing and analysing the interviews was time consuming and dependent on the researcher's interpretation. Some of the themes were checked with three of the young people during their second interviews in year 11, but the capacity to carry out second interviews was restricted, due to time constraints. Further research of this type might be enhanced by involving a team of researchers to allow for checking out of the coding and formulation of categories and the themes generated. There was some attempt to adopt an iterative approach involving the simultaneous collection and analysis of data, but this was limited by the restricted time scale. Similarly it was not possible to pursue to the point of 'saturation' in the data collection and analysis as advised by the grounded theory methodology, because of the limitations of the fieldwork. Additional categories and themes were continuing to emerge from the data which there has not been time or space to explore.

An example of this were references made by a number of the young people to the support and influence they received from their parents at home or in interactions with the school (a positive sense of self has been associated with perceived social support from parents, Antle, 2004). This would offer a good area of further research.

Despite initial attempts to also carry out interviews with disabled pupils in non-resourced mainstream schools, this was not possible in the time frame available. However this would be an appropriate avenue for future research, since the presence in the school of a 'resourced PD provision' seemed to be a relevant factor in perceptions that these pupils were somehow different, and the absence of such provision in a mainstream secondary

school may have a significantly different impact on their experience (see Bourdieu, 1992, 'rites of institution').

As mentioned in Chapter 3, some of the children raised issues which were very significant and personal in their lives which, in the context of the present research, I was unable to follow up with them directly, although with their permission I mentioned my concern or their issue to their teacher or the link educational psychologist for the school. Again, this indicates a need for more action based research with these young people which can draw on their agendas more directly and allow for the role of both researcher and supporting professional.

The present study makes a contribution to inform policy and practice at a number of levels. At a local level it provides clear messages to the school that these pupils attended regarding transition, friendship, bullying, being listened to and promoting an affirmative model of disability. It reinforced the need for disabled pupils to have more appropriate role models and for there to be more access for them to disabled adults in schools and as researchers. An important finding was that, when feeling valued and listened to by someone who they felt may share some of their experience of disability most of these pupils were keen and able to explore their experiences and raise issues for joint problem solving. For others, there is a need to explore a shared language to discuss their individual needs within an affirmative model of disability.

In addition, the findings can contribute to thinking and policy development in the local authority regarding policy issues which involve resourced provision as an option for addressing the needs of these pupils in inclusive settings, drawing on this small scale study alongside other evidence and perhaps identifying the need to commission more. These pupils were almost unanimous in their criticism of being educated at some geographical distance from their local community, which impacted on friendships, being perceived as 'different' and extra-curricula opportunities at school. It is important to consider other, more local options to meet their educational and physical needs.

At a more macro level this study can also contribute both theoretically and methodologically, through the set of emerging concepts, to the body of research evidence which has used qualitative methodologies to seek the views of disabled pupils.

How the views expressed by pupils will eventually affect policy development I feel has yet to be determined; what happens if the young people's views clash with those of their parents, or with those administrators/academics/professionals who think they have an evidence base for what is most efficient/efficacious/value for money? What if different groups of young people think or want different things? Schools need to view the messages they receive from their pupils as "a significant opportunity to review the capabilities and identities of children and young people in schools and society" (Ruddock, 2006, p. 133). This is a substantial area for future research, both in schools and at local authority and central government level.

In this research I have addressed the key questions outlined at the end of Chapter 1. The experiences described by these disabled pupils attending resourced provision in a mainstream secondary school have been presented, using a qualitative approach, which allowed for themes to be drawn from the pupils' descriptions, which were grounded in the data collected. The issues raised by these pupils' views have been explored and feedback from the pupils themselves suggested that they engaged readily and appreciated talking to a disabled researcher. A summary of these issues will be shared with the participants, school and local authority.

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Appendix 1: THE RESEARCH CONTEXT

The study took place in a mainstream secondary school in a large shire county in the south of England, which is additionally resourced by the local authority to take pupils with ‘significant physical disabilities and associated learning difficulties’. The school is a mixed comprehensive which, at the time of the study had a total number on roll of 856 pupils. There were very few pupils from ethnic minorities. It drew many of its pupils from a catchment area where a relatively low proportion of adults had received higher education. The proportion of pupils who were eligible for free school meals was about average. The school was designated a community school and provided a wide range of educational and leisure opportunities for the local residents. There were around 30 pupils with physical impairments affecting mobility, about 25 of these having statements of special educational need. The proportion of pupils with other special educational needs was above average.

The school had been adapted by the local authority to be as physically accessible as possible. It had two floors with lifts to the second floor areas and ramping throughout. Main doors were automatic or were fire doors held back in the open position most of the time.

The pupils in the resourced provision were full members of the tutor groups within the school and attended registration and all subject lessons along with the other children in their year group. The facilities in the learning support department were available to any pupil in the school as required and included a fully equipped physiotherapy room and learning support classroom. There were accessible toileting and showering facilities in this area and other accessible toilets around the school, though any person requiring hoisting would need to go to the learning support department.

OFSTED (June 2004) described the overall effectiveness of the school as ‘good’ with ‘outstanding’ resourced provision which ‘benefits all students’. The inspection stated that ‘the students display understanding, friendship and acceptance towards their peers with disabilities’ and that ‘the school makes outstanding provision for students with a wide range of special educational needs who are effectively integrated into mainstream lessons’.

Appendix 2: PUPIL DETAILS

Participant	Age	Impairment
1	8.12.04 1 st interview 13y 4m 9.01.07 2 nd interview 15y 7m	Cerebral palsy, electric wheelchair user
2	3.12.04 1 st interview 13y 5m 13.02.07 2 nd interview 15y 7m 23.05.07 3 rd interview 15y 11m	Cerebral palsy. Purine Nucleoside Phosphorylase (an immune deficiency disorder) Successful bone marrow transplant in 1995, electric wheelchair at first interview, manual at second and third
3	3.12.04 1 st interview 14y 1m 9.01.07 2 nd interview 16y 2m	Hydrocephalus, with shunt, ambulant with walker
4	3.12.04 1 st interview 13y 8m	Cerebral palsy of mixed type, mild learning difficulties, ambulant
5	25.06.07 1 st interview 14y 8m	Duchene Muscular Dystrophy, electric wheelchair user
6	12.06.07 1 st interview 15y 4m	Cerebral palsy of mixed type affecting all four limbs. Ambulant
7	25.06.07 1 st interview 14y 7m	Congenital shortening of both lower limbs (effectively no legs) with neopathic bladder and bowel. Scoliosis. Manual wheelchair user
8	3.06.07 1 st interview 14y 9m	Multiple bony exostoses, manual wheelchair user
9	26.06.07 1 st interview 14y 1m	Flexed flexion deformity of hips, scoliosis, congenital nystagmus and neuropathic bladder and bowel difficulties. Ambulant
10	25.06.07 1 st interview 14y 2m	Cerebral palsy, spastic quadriplegic, electric wheelchair user

Appendix 3: INTERVIEW QUESTIONS

12.06.07

Main questions are in bold, followed by prompt questions

I would like to talk about your experience of being a disabled pupil in this school. Is that OK?

Tell me about yourself

If disability not mentioned, ask about this

Tell me about being at school

How is being at this school different from your previous one?

What has been good about going to a large secondary school?

What do you think about the other people here in the school?

Teachers, DLAs, other students

Has it been easy to make friends?

What are some of the things that make it easier to make friends at school?

What are some of the things that make it harder to make friends at school?

What makes a good friend for you?

Do you have a chance to see any of your school friends after school hours?

Do you see other friends out of school?

How do you feel about your learning in school?

How do you feel you are getting on in classes?

How do you feel about your academic achievements in school?

Tell me about receiving support.

How does this affect your experience in class?

What is it like having a DLA with you a lot?

How does the DLA know when to help you?

What are the teachers like with you? How does this compare with other pupils?

How much do other pupils help you?

What do you see yourself doing when you leave school?

How can people help you to achieve this?

How do you feel about the prospect of leaving school?

How do you think society treats people with disabilities generally?

Issues to ask about if not covered (*These emerged during the iterative process of analysis*)

Bullying

Being with other disabled pupils

Support of friends

Independence

Receiving help (LSAs)

Significant events in school life

Words to describe self

Process Questions

Tell me what it's been like to take part in this interview

How do you feel about the word 'disability'?

How has it been having a disabled person asking you about disability issues?

How do you feel about what you have told me?

Is there anything you would like me to leave out?

Were you comfortable with the video?

Appendix 4: PARENT LETTER (FIRST INTERVIEW)

Dear Parent/Guardian,

Re: Research into the views of young people with physical difficulties on their school experience

I am inviting your son to take part in the above study. I have asked the school to send you this letter and I would be grateful if you would take the time to read it to help you decide if you would be willing for your child to participate.

I am a senior educational psychologist, working for Hampshire local education authority and have a physical disability myself. This research project is part of my doctoral research studies.

There is very little existing research which asks young people themselves about their experience of school, as a disabled person, and how they feel about the support they receive or would like to receive. I want to consider both their academic (work related) and social experience. I am hoping that the research will enable the voices of young disabled people to be heard and thus highlight their needs within the education system.

The questions will be open-ended to allow your son to say as much or as little as they choose, topics covered will include their experience at school, their friendships, what they feel about themselves and their hopes for the future. I also want to ask for their views on myself as the researcher and the method used. The whole interview will be less than an hour.

The interview will be confidential to the individual and your son is free to withdraw at any stage, without giving any explanation. The teachers will be fully aware of the research at all times, although they will not be present at the time of the interview, nor will they know what any individual has said.

The interviews will be filmed, to ensure everything that is said can be remembered; after the research is completed the tape will be destroyed. Once the whole project has been carried out, the school and each individual participant will receive a summary of the findings.

I do hope you will support your son participating in this project and will be interested in its findings. I will be asking your son for his consent to participate, but I also need your consent for him to be able to do so. Please fill in the enclosed consent form and return it to the school (Mrs D.....) by 5 June 2007. If you have any questions, please contact myself, Gay Keegan, on1496,

Yours sincerely,

Gay Keegan

Senior Educational Psychologist

Appendix 5: PARENT LETTER (FOLLOW-UP INTERVIEW)

Dear Parent/Guardian,

**Re: Research into the views of young people with
physical difficulties on their school experience**

Your son took part in an interview with me when he was in year 9, which explored his views about his experience of school and how he felt about the support he received or would like to receive. At the time I told the pupils I interviewed that I would like to speak to them again, to check the comments they had made and explore some issues in greater depth. I am now in a position to do this and would like to meet with your son, if he is happy to do so.

The interview will be confidential to the individual and your son is free to withdraw at any stage, without giving any explanation. The teachers will be fully aware of the research at all times, although they will not be present at the time of the interview, nor will they know what any individual has said.

The interviews will be filmed, to ensure everything that is said can be remembered; after the research is completed the tape will be destroyed. Once the whole project has been carried out, the school and each individual participant will receive a summary of the findings.

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Yours sincerely,

Gay Keegan

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The interview will be confidential to the individual and your son is free to withdraw at any stage, without giving any explanation. The teachers will be fully aware of the research at all times, although they will not be present at the time of the interview, nor will they know what any individual has said.

The interviews will be filmed, to ensure everything that is said can be remembered; after the research is completed the tape will be destroyed. Once the whole project has been carried out, the school and each individual participant will receive a summary of the findings.

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Yours sincerely,

Gay Keegan

Senior Educational Psychologist

Appendix 6: ANNOTATED TRANSCRIPT EXTRACT

- 343 P: Well they don't physically like kick me
344 around but they see someone... they see
345 someone in a wheelchair that they think they
346 haven't got any feelings so I'm going to pick
347 on him and he'll just take it and I'm like no,
348 I'm not going to put up with it. I think a lot of
349 people haven't seen me in my true form
350 because I keep it masked but it's getting to the
351 stage where if one more person acts dis... um
352 acts wrongly towards me its going to be the
353 true fellow in me will be revealed... and I'll
354 just obliterate them and they wouldn't know
355 what hit them
356 G: [Laughs] OK so you've come here from
357 another school. Has it been easy to make
358 friends here?
359 P: Nope, nope
360 G: Right tell me about that
361 P: Because Paul is half normal and half
362 disabled. With the normal side I like deal
363 because I'm like thinking to myself, no I'm
364 normal but I'm in a wheelchair
365 G: Erm hum

BULLYING
Difference - lesser being
passivity
establishing AGENCY

retaliation
super-being inside
- agency

FRIENDSHIP

IDENTITY
identity issues
normal = not different
- feels like this
sees self as 'normal'
appears different
happens to be
DIFFERENCE

- 366 P: But the normal people don't seem to want
 367 to learn sort of thing, so I like to stick around
 368 with my own kind
 369 G: Right, right
- 370 P: I know I shouldn't talk like this but it's
 371 when I go to, like they're one race, we're
 372 another
 373 G: Erm hum
- 374 P: I don't know whether that's how you feel I
 375 don't know, but that's the way I feel that
 376 they're one race and we're another and we're
 377 the lower one in society
 378 G: Right, right erm OK
- 379 P: It's horrible
 380 G: So do you have friends at school, are they
 381 mostly disabled pupils?
- 382 P: They're all blooming disabled pupils that
 383 are my friends
 384 G: Right
- 385 P: Because I find that they're easy to talk to
 386 G: Right
- 387 P: So if I get in any dilemmas like... like, I'm
 388 stuck, I can't get out the lift or something,
 389 they know what I can do and what I can't do,
 390 they sort of expect me what to do and when
 391 I'm stuck, while normal people would just be
 392 like huh, deal with it

doesn't think 'normal'
people want to know
identifies with other
disabled pupils

not appropriate
DIFFERENCE
us/ them

DI - disabled interviewer

DIFFERENCE
us/ them
feeling less valued

NEGATIVE VIEW OF DISABILITY/
DIFFERENCE

OTHER DISABLED PUPILS

Associates exclusively
with other disabled
pupils

shared experience

DIFFERENCE
understood by other
disabled

don't understand

393 G: Erm, when you say you chose somebody to

394 go in the lift with you didn't you?

395 P: Yeah

396 G: Would that be a friend?

397 P: Yeah, yeah it would be but if it wasn't for,

398 not the school rules, but the school sort of

399 allocate that we have to have an able bodied

400 with you and I'm like, I can go in on my own

401 thanks, I don't see the point of relying, shall

402 we say, on other people to do things. Well I

403 rely on em all day because I'm used to it but

404 I'm fed up with relying on people to do it

405 G: Erm hum

406 P: I mean I have a little blue book for the staff

407 to write in and people are like, 'What's that

408 little blue book?' 'It's none of your business',

409 'What's that little blue book?' 'It's none of

410 your business', and in the end I'm like 'fine,

411 fine I'll tell you what it bloody well is'

412 G: Erm

413 P: [3 seconds] Because there's normally some

414 things you don't want to reveal and then they

415 keep probing you for information until you tell

416 them and I'm pissed off with it. Sorry about

417 the language but

418 G: OK. Do you ever see any of your school

419 friends after school, outside school?

school rules restrict
choice

Reflections on Health and
dependency safety
helper as category / tool

Doesn't want to have
the help if he feels he
doesn't need it

RECEIVING HELP - necessary
so tolerated
feelings

BULLYING
lack of privacy

enquiry from others,
don't understand

Annoying / angry

Lack of privacy -
vulnerability

strength of anger

420 P: Not in this school but I see one of them
 421 from the other school
 422 G: Right, the school before you came here
 423 P: Yeah
 424 G: Right
 425 P: Because I'm a bit annoyed with the people
 426 here anyway during the day so I think what
 427 the hell's the point, I know they would be
 428 different out of school because they would be
 429 them but they have to watch themselves
 430 because of they're in school. But I think to
 431 myself like...
 432 G: Erm hum
 433 P: And where I'm a 14 year old disabled...
 434 disabled person I'm... I can get cross quite
 435 easily because... because I'm 14 and I'm a
 436 teenager, somebody who grew up in the area
 437 and then uh if people cross me I'm like, I just
 438 open up and like have a go at them, go back
 439 into myself and then walk off basically or
 440 wheel off
 441 G: Erm hum, erm hum. Do you go to anything
 442 out of school, leisure activities?
 443 P: Yeah I do, I go to PAL, which is a thing
 444 that they do loads of different, lots of different
 445 um activities
 446 G: Right, do you enjoy that?

FRIENDSHIP
 Doesn't see secondary
 friends out of school
 Friend from primary
 school

still angry about the
 perceptions of other
 pupils in school

sees other pupils
 'in role' in school

Falls out easily with
 people? - teenager
 and disabled

expresses feelings more
 in home neighbourhood -
 more agency?
 expresses his anger
 (doesn't want to forgive?)

use of generic term,
 corrected to include
 and DISABLED IDENTITY

LEISURE

DISABLED CLUB

- 447 P: Well some of it I do but then again some of variable enjoyment
 448 it I don't. I mean they do rifle shooting and...
 449 and... and botcha which is bowls, basically,
 450 and... and bowling and pool and all that. I chooses the activities
 451 enjoy all that sort of thing but then they do a he wants to engage
 452 stupid thing like horse riding and... I don't go in
 453 for all of that - can't do this?
 454 G: Right, right therefore 'stupid thing'
 455 P: I go for the stuff like bowling and stuff
 456 where I know I'll be able to do it importance of feeling
 457 G: Yeah, yeah successful - having agency
 458 P: But horse riding, not only that I don't like
 459 animals anyway, but I wouldn't like to be... expects failure
 460 the horse bucking me off or something - fear of horse
 461 G: Yeah
 462 P: And being, not being able to catch myself aware of own
 463 and hurt myself even more than any one else limitations because
 464 would because they can like help themselves of physical
 465 G: Erm hum, OK. So how do you feel about difficulties
 466 your learning in school?
 467 P: My learning! It's brilliant LEARNING
 468 G: Right
 469 P: The learning here, the learning scheme is learning is
 470 excellent but it does annoy me that you have excellent
 471 to do stuff like religious education. I know RELEVANCE OF
 472 I'm... I know I shouldn't be like this but if THE CURRICULUM
 473 you're not religious at all why the hell do you

474 have to learn about it? If you're not religious
475 then why do you have to learn about it
476 especially like Jews and Buddhists? If it was
477 like Christianity, which... which it mostly is,
478 I'm fine with Christianity because that is our
479 main religion...

Complaints about
learning about
other religions
- personal opinion

480 G: Erm

481 P: ...because we're all like, we live in a
482 Christian country but if it's like Muslim and
483 Jews and Buddhists and [3 seconds] Jehovah
484 Witnesses and Scientology and... I just don't
485 see the point

486 G: Right, right. Well you certainly know what
487 all those are don't you now [laughs]

488 P: Yeah and I mean like the worst one, PE,
489 why the hell do we have to do PE, we're not
490 going to be running around

Doesn't like PE
- can't do what's
offered by the
curriculum

491 G: Right, right

492 P: So what's the point and they... and
493 sometimes they forget that that they have
494 disabled people in the classroom 'oh, let's do
495 this, oh, wait, sorry we can't because we've
496 got a disabled person in the room'

DIFFERENCE
- over looked by
others - teachers
negative views
of disabled pupil
- prevents class
activity

497 G: Erm

498 P: And I'm like, huh, if you're going to get me
499 to do this crap subject you've got to get me to
500 do something. And last year it was really

RELATIONSHIPS
Not being included
in the lesson